

An aerial photograph of a city, likely St. Louis, showing a winding river (the Mississippi River) on the left side. The city grid is visible, with various buildings and infrastructure. The title 'THE WHOLE COMMUNITY CATALOGUE' is overlaid on the top portion of the image in large, white, serif capital letters.

THE WHOLE COMMUNITY CATALOGUE

Welcoming people with disabilities
into the heart of community life

Compiled & Edited by THE WHOLE COMMUNITY COMMUNITIES, INC.

THE WHOLE COMMUNITY CATALOGUE

**Governor's Planning Council on
Developmental Disabilities**

300 Centennial Building
658 Cedar Street
St. Paul, Minnesota 55155

COMPILED AND EDITED BY DAVID WETHEROW

COMMUNITAS, INC.
Manchester, Connecticut
USA

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Communitas, Inc.
Box 374
Manchester, Connecticut 06040 USA
Telephone: (203) 645-8034

and

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COMMUNITAS, INC.

The *Whole Community Catalogue* is as a project of Communitas, Inc. Registered as a 501 (c)(3) non-profit in Connecticut, Communitas is an international network of people dedicated to enriching our communities, neighborhoods, associations, schools and workplaces through full inclusion and participation of people who have disabilities.

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THE WHOLE COMMUNITY CATALOGUE

Foreword

BY

DAVID B. SCHWARTZ, EXECUTIVE
DIRECTOR, PENNSYLVANIA
DEVELOPMENTAL DISABILITIES
PLANNING COUNCIL

*David Schwartz is the author of
Crossing the River: Creating a
Conceptual Revolution in
Community and Disability,
Brookline Publishing, 1992*

There is a conceptual revolution taking place today in the field of services to people with disabilities. This revolution may ultimately prove to be equal in historical importance to the one which caused us to turn away from institutions two decades ago. Once we saw institutions as the answer to human need. Finally we recognized their obvious and overwhelming flaws. More recently we viewed community service programs such as group homes, day programs and sheltered workshops as the answer. Yet we are finally starting to acknowledge that this approach, too, has started to show its limitations, and even its tragic failures.

Over the past decade immense progress in service-building has been made. In most states and provinces, parents may find early intervention and education, family support, employment training, and small group living arrangements. Yet while we continue to build and expand the community service system, a sense of disquiet seems to be growing among thinkers in the field. Many of the services that we thought so innovative only fifteen years ago betray an institutional character from today's perspective. They tend to have a monolithic character which stands apart from, and may even displace, true community enterprises. Sheltered employment programs we started barely fifteen years ago are starting to look like places of confinement. Staff turnover in some group home programs exceeds 90% per year. Mental health critics are seizing upon the obvious failure of a poorly-implemented effort at deinstitutionalization and agitating for a return to the safety of the asylum.

Faced with such obvious problems, it is apparent that the original plan for community service systems has not been realized, despite some obvious gains. These problems, in fact, may signal a failure in the fundamental *idea* of creating a system to administer comprehensive and compassionate care. Such cracks in the paradigm, or conceptual framework, often appear when the existing paradigm is exhausted and the ground for the acceptance of a new one is in preparation.

Our particular challenge today is not how to expand or refine the community services system but how to *counter* it with something completely different by nature. The challenge is to move from the familiar world of trying to build a caring service system into trying to elicit and support caring within the subtle fabric of human relationships.

The Whole Community Catalogue is an introduction to the thinkers and *doers* who are at the leading edge of this paradigm change. It is a practical guide that provides families, friends and human service workers with tools and ideas for the next step. It is a welcome addition to the field.

THE WHOLE COMMUNITY CATALOGUE

Dedication

I grew up in a world in which there were *no* children with disabilities. I went to eleven different schools in five communities, and I never met a child who used a wheel-chair, or met a child who could not see, or hear, or who had great difficulty learning. Then, when I was twenty-five, I wandered onto the grounds of a "State Home and Training School" in Colorado, and discovered where the children had been. This book is dedicated to those children, and the ones who follow them, and to their families and friends.



My life has been blessed by friends, touched by love, and enriched and guided by teachers. Each one finds expression in this work-Special thanks to Richard Asselin, Tom Baker, Deanne Bammer, Charles Bauman, Andy Baxter, Pat Beeman, Mike Bessey, Jerry Boucher, Charles Burkhouse, Dan Chafe and Jennifer Partridge, Alan Charr, Peter Clutterbuck, Jim Derksen, Peter Dill, Lillian Doig, George Ducharme, Gunnar and Rosemary Dybwad, Alan Etmanski, Doris Fillmore and Alan McWhorter, Marsha Forest and Jack Pearpoint, Lee Foster and John McGough, Phil Goodman, Sharon Gretz, Harry Havey, Jay and Delores Jarrell, Tom Kohler, Scott Klassen, Jay Kline, Peter and Marilyn Krahn, Pamela and Harry Landon, Mary-Anne Langton, Brian Law, Sharon Lawrence, Susan Lewis, Leon and Kay Linquist, Marlon, John and Elizabeth Little, Zana Lutfiyya, Cheryl Martens, Father Patrick Mackan, Wayne Marshall, John McKnight, Beth Mount, Lee Norbeck, John O'Brien and Connie Lyle, Sarah Page, Jake Pauls, Ted and Carole Powell, Randy Rehbein, Ed Roberts, Sid Rogers, Mary Rusk, Marlene Scardamalia and Carl Bereiter, Nicola and Catherine Schaefer, David Schwartz, Ren Shearer, Judith Snow, Helen Steinkopf, Jeff Strully, Faye, Marvin and Amber Svingen, Alan Sweatman, Don Trites and Bev Baker, David and Ruth Truran, Doug and Deirdre Watson, Herb, Ann Bill, Ruth, and Renee Wetherow, Sherrill, Alia, Dante and Owen Wetherow, John Winnenberg, Wolf Wolfensberger, David Wright, and Jack Yates.

David Wetherow
Winnipeg, Manitoba
May 15, 1992

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Preface

BY

JUDITH A. SNOW, VISITING
SCHOLAR, CENTRE FOR
INTEGRATED EDUCATION AND
COMMUNITY, TORONTO,
ONTARIO

*"We see people
forming inclusive,
intentionally mu-
tually supportive
developments
where vulnerable
people anchor
circles of caring."*

IN THE SPIRIT OF INCLUSION

There is in the world today a vibrant new culture. It is young and rough, but its birth has been true, and with proper nurturing, its life and growth promise to be dramatic. It is the culture of inclusion.

The culture of inclusion begins in the affirmation that all human beings are gifted. This statement sounds strange to many ears because our traditional world reserves the adjective "gifted" for only a chosen few whose talents and abilities, usually in very circumscribed ways, impress, enlighten, entertain or serve the rest of us. The inclusion culture views giftedness much differently.

We affirm that giftedness is actually a common human trait, one that is fundamental to our capacity to be creatures of community. Gifts are whatever we are, whatever we do or whatever we have that allows us to create opportunities for ourselves and others to interact and do things together - interactions that are meaningful between at least two people. So, for example, if you are interested in an evening's fun of softball and you have six people to form your team, you have an opportunity to offer to several people, including the bystanders who might just end up watching. But you can't play softball without at least seven people per team, so when the seventh person comes along, that person's presence is a gift to many other people, even if she or he doesn't play very well. Our *presence* is the fundamental gift that we bring to the human community. Presence is the fundamental of all other opportunities and interactions-of everything that is meaningful in our lives.

Also fundamental to each person's presence is each person's difference. In fact presence is not possible without difference since even on a very simplistic level difference is essential to life (none of us would be here if the male and female difference did not exist). Meaning depends on difference as well, since if we were all the same there would be nothing to share or contribute to one another. Therefore, not sameness, but presence and difference are fundamental to life and community.

In addition to our presence, each of us has a grab bag of other ordinary gifts that allow us to create and participate in daily opportunities. From getting up, making breakfast, washing dishes or loading a dishwasher, talking on a telephone, writing on a piece of paper, listening to another per-

IN NORTH AMERICA THE
CANADA GEESE FLY SOUTH
EVERY FALL AND NORTH IN
THE SPRING, COVERING
HUNDREDS OF MILES EACH
DAY. THE BIRDS FLY IN A V-
FORMATION, WITH ONE BIRD
IN FRONT FOLLOWED BY TWO
DIVERGING LINES OF FLYERS.
THE LEAD BIRD BREAKS THE
WIND'S RESISTANCE FOR THE
TWO BEHIND, WHO IN TURN
ARE SHIELDS FOR THE BIRD
BEHIND EACH OF THEM, DOWN
TO THE END OF THE LINE. BUT
IN THE COURSE OF EACH
FLIGHT THE LEADER DROPS
OUT OF POSITION TO GO TO
THE END OF THE LINE AND TO
BE REPLACED BY ONE OF THE
FOLLOWING BIRDS —
OVER AND OVER AGAIN. IN
THIS WAY, NO ONE BIRD IS
EVER LEADER FOR SO LONG AS
TO BE EXHAUSTED OR TO
DENY OPPORTUNITY TO
ANOTHER BIRD. IN TURN,
EACH BIRD IS THE GUIDE.
THIS IS A MODEL OF ORGANI-
ZATION OF A COMMUNITY
WHERE THE GIFTS OF ALL
BENEFIT EVERYONE.

son, getting from one place to another, enjoying music, expressing an opinion, going to a meeting, playing with a baby or having fun with a friend, a variety of simple activities taking place in ordinary places on ordinary streets make up the fabric of the vast majority of our work, family life, private life and public contribution.

Beyond ordinary giftedness there is extraordinary giftedness, the kind that extends opportunity for interaction and meaning to a larger number and variety of people. One person is not just nice to be with but is a truly funny comedian; another doesn't just get around but dances on skates beautifully. Another not only shows up for the PTA regularly but has engaging ideas that are changing the face of the local school board.

Each person has a variety of ordinary and extraordinary gifts. The people whom we call handicapped are people who are missing some typical ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.

In fact it is not just that walking is a gift and not walking is not a gift or that knowing how to put your clothes on right is a gift and not knowing is not a gift. Rather walking is a gift and not walking is also a gift; knowing how to dress is a gift and not knowing how to dress is also a gift. Each creates the possibility of meaningful interaction.

The affirmation of giftedness creates the need for us to organize our homes, schools, work places and other establishments differently and this is what has given birth to the inclusion culture. In the past we became efficient at separating people into classifications of supposed sameness. Now we are struggling to build our community life up from the foundation of our enriching differences.

In the schools we see classrooms of creative learning being founded on the support that children and teachers can offer to each other in the spirit of co-operation. In housing we see people forming inclusive, intentionally mutually supportive developments where vulnerable people anchor circles of caring. In decision-making bodies we see people taking leadership in turns based on their energy, experience, desire, and availability, able to give way to one another at the right time.

Of course these efforts at inclusive community are new, and isolated and foundationally weak. But the seed has been well sown. These efforts support each other and inspire others to change. The story of inclusion has a vigorous beginning and promises a very creative future.

THE WHOLE COMMUNITY CATALOGUE

Introduction

BY DAVID WETHEROW

Across North America, people with disabilities, and their families and friends, are looking for ways to become more deeply connected to the life of the community. At conferences and workshops, in schools and living rooms, people are beginning to talk less about "community services", and more about community itself.

In just over two decades, we have seen the "state of the art" shift from large asylums, to regional "centers", to institutional services located in the "stage setting" of the community, to more individualized, dispersed community services.

Now, we seem to have reached another turning point. As we talk with friends involved in this work, we hear stories and ideas that tell us that major changes are taking place in the way we think about:

The **people** we call disabled, their needs and gifts,
The **community**, and its capacity to welcome and
accommodate all of its members, Our **families**
and **ourselves**, and, The nature of our **collective**
responsibility for
vulnerable people.

As people move closer to home, their families and friends have begun to look *beyond* community services and towards the community itself. They are seeking the capacity in communities and networks of friends. They are learning to recognize and celebrate the gifts of vulnerable people. And they are working out more appropriate relationships to service systems and people with specialized knowledge.

These are timely events. Governments at all levels are faced with increasing competition for public funds, and some service systems are nearing exhaustion. In many localities, services are cut back as governments struggle to overcome accumulated deficits. State-of-the-art community services are still the exception in many places, and they are always vulnerable to challenge by competing interests. We don't believe that it's a particularly safe bet to base the futures of vulnerable children and adults on the prospect of continued growth in the service sector. We do believe that broadening the base of commitment, building strong connections to the community, inviting the community's hospitality and commitment, and shifting the focus from needs and deficits to gifts and capacities is a good investment of time and attention.

The Whole Community Catalogue has been compiled to reflect this movement towards full community inclusion, and to support and celebrate it.

HOW THE CATALOGUE GOT STARTED

At community conferences and workshops, conversations inevitably turn to the books, stories, ideas, and connections that people have found to be useful. This personal sharing is fruitful, but has its limitations. The opportunities to get together are precious, but they are also infrequent, and there is a tendency for the stories to stay within a small circle of friends, or the slightly larger circle of people who can afford to attend community conferences and training events.

But ordinary families, friends, church congregations, and community associations also need access to tools and ideas. They *are* the "front line", working day by day to create solutions for the people whom they care about. Ultimately, if the work of inclusion can only occur under the auspices of expert "community-builders", we are defeating our own purposes, and working against our own principles.

In the Fall of 1987, at a conference in Keene, New Hampshire, we started thinking about creating a catalog of community-building ideas. People who had seen the *Whole Earth Catalog* immediately figured out what a "whole community catalog" would look like and how it would work, so we pursued the idea.

During one of the conference breaks, I asked John McKnight, "What are the essential texts in community organization?". John named two books which became part of my working library (the books were Saul Alinsky's *Rules for Radicals*, and *Organizing*, by Cy Kahn).

George Ducharme told me about a book that he was excited about: *Community Dreams*, by Bill Berkowitz. Beth Mount talked about a Christopher Alexander, a California architect who was developing a "pattern language" for designing neighborhoods and buildings that *worked* on a human scale. Tom Kohler talked about a book on the origins of the US civil rights movement. Each person we talked to had another book, or article, or story that they had found useful and inspiring.

George Ducharme, president of Communitas, Inc., took the idea and ran with it. He was encouraged by Ed Preneta, Executive Director of the Connecticut Developmental Disabilities Council, and in 1990, the Council awarded Northspring Consulting and Communitas a grant to create the *Catalogue* and produce the first edition.

We are deeply grateful to the Connecticut Developmental Disabilities Council for making this publication possible. Proceeds from this edition will be used to finance future editions of the Catalogue.

THE WHOLE COMMUNITY CATALOGUE

RESPECTS TO STEWART BRAND

Back in the 1960's, a man named Stewart Brand conceived the idea of a catalog that would give people "access to tools and ideas" for social change, self-reliance, and personal and community development. Brand invited readers to contribute the tools and ideas that *they* thought were important.

The Whole Earth Catalog became a widespread "correspondence" — a community bulletin board for explorers. It connected all the people who didn't manage to make it to San Francisco, or Esalen, or Tibet, to the people who did. It contained *thousands* of good ideas, and helped shape the thinking of an entire generation. *The Whole Community Catalogue* follows respectfully in the *Whole Earth* tradition.

The Whole Community Catalog is like a work-in-progress. As John McKnight reminds us, community is always changing, evolving, and never finished. We'll always be finding new tools and replacing or modifying old ones. And we want to listen and learn, as much as to share what we've learned.

We are looking for the best books, articles, videotapes, ideas, examples, and stories that you've discovered. We're looking for items that empower people and lead away from things bureaucratic.

In Stewart Brand's words, "We'll only review the things we think are great. Why waste your time with anything else"? If you were going to recommend one book, or article, or idea to a friend, what would it be? Share the ideas and examples that give you energy and inspire your creativity.

Tell us about the things you think are great, and *why*. Write it as though you were writing a letter to a friend. Include brief quotations that capture the essence of the work.

<p>In the USA, mail submissions to:</p> <p>Communitas, Inc. Box 374 Manchester, CT 06040 USA</p>	<p>In Canada, mail submissions to:</p> <p>The Community Institute Box 23036 1315 Pembina Highway Winnipeg, MB R3T 2B6</p>
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THE WHOLE COMMUNITY CATALOGUE

1.

RE- VISION- ING THE PEOPLE

"We sailed for miles an' miles. An' we talked. Properly. An' we didn 't half laugh. We liked each other. An' isn't it funny, but if you're with someone who likes y', who sort of, approves of y', well y' like — like start to grow again. Y' move in the right way, say the right thing at the right time. An' you 're not eighteen or forty-two or sixty-four. You're just alive.

*- Shirley Valentine
(from the play by
Willy Russell)*

Building community challenges us to find, create and nurture spaces in which all people are valued and appreciated for their gifts as beings on this earth. Sadly, many of us live much of our time in a material world in which worth must be constantly earned and measured in terms of our capacity to produce, earn money, accomplish, and compete with others for some elusive goal which we never quite attain. In this kind of world, we live as objects, in deep sorrow that some sacred part of ourselves and our communities is lost or buried.

People with disabilities often live with even greater despair, because their inherent value as human beings goes unseen and unappreciated. They are repeatedly rejected and abandoned because they fail some false standard of perfection. Many may be valued only in terms of their capacity as clients to generate money for human service systems. As a result of many forms of devaluation, people with disabilities are often treated as objects to be processed, controlled, fixed, or discarded, and consequently, they may live with great anguish and loneliness.

Re-visioning the people invites us to see people in a different light, as people with strength, beauty, courage, and inherent gifts, who simply belong. Seeing differently is hard work because we must push back against so many of the forces such as labeling, segregation, and stereotypes, that block us from developing a positive vision for people.

Re-visioning the people requires us to reclaim and revalue each person's story, interest, wisdom, path on this earth, and then commit ourselves to the journey of restoring and recreating a life of meaning and contribution for each person. Re-visioning requires us to resist any service practice, personal prejudice, or institutionalized criticism that interferes with the work of that restoration.

Re-visioning the people goes hand-in-hand with re-visioning ourselves and our communities, for we must find many ways to shelter and protect the sacred parts of our lives in which we enjoy, appreciate, live, care, and work together in constructive ways. People with disabilities are challenging us to build a different world in which the sacred in all of us is restored and encouraged.

- BETH MOUNT

AND THEN CAME JOHN



There is in each life a quality, a special fragrance of the bone and of the flesh; individual, unmistakable, exactly as it issued from the Spirit's mold. A quality which nothing can in any manner alter.

- Kenneth Patchen

And Then Came John; Scott Andrews; 1987; (videotape, 36 minutes, color); **\$50.00** (parents), **\$400.00** (organizations) from: Telesis Productions International, P.O. Box 948, Mendocino, CA 95460; (707) 937-3048

And Then Came John chronicles the triumphant story of John McGough — from his birth with Down Syndrome thirty years ago — through rejection and prejudice in urban America — to his rebirth as an artist, musician, and much loved personality in a warm and accepting community on the Northern California Coast.

I first met John McGough and his family at a community conference in Winnipeg. His mother told the story about his seeing a script for the play Agnes of God. John said, "It's the same as Sleeping Beauty — the feeling is exactly the same — strong love wakes people up." This is a film that wakes people up. It is also the only film I feel entirely comfortable showing to parents. It brings home the message that what we need to make community work is at hand — within the reach of perfectly ordinary people. Sometimes, people who see the film express regrets that they don't live in Mendocino — an idealized vision of a small town. But then they start asking the question, "How can we find the 'Mendocino' in our own fami-

lies, friendships, neighborhoods, churches... ?" John's younger brother, Andy, reflects: "John exemplifies something that is safe up here, and could be safe anywhere."

John McGough's family and friends in Mendocino have discovered the simple gift of allowing him to be exactly who he is, and celebrating his identity. And a gift is returned to the community: everyone who encounters John McGough finds that they are allowed to be exactly who they are, which (I've felt it) is a blessing indeed.

"An absolute treat.... only the devil could remain untouched after seeing it."

Jack Lemmon

Where is our comfort but in the free, uninvolved, finally mysterious beauty and grace of the world we did not make, that has no price? Where is our sanity but there? Where is our pleasure but in working and resting kindly in the presence of this world?

- Wendell Berry
Standing by Words

Once, Lee Foster (John's mother) enrolled him in a small local "day" program — nice setting, small jobs, nice people. But each evening, John came home in some distress.

Lee: What's happening, John?
John: It's too hard for me there.
Lee: Is the work too hard?
John: No, the work's not too hard.
Lee: Are people giving you a hard time?
John: No, people aren't giving me a hard time.
Lee: John, what does it *feel* like for you to be there.
John: I feel more retard there.
Lee: What does it feel like to be "retard"?
John: Retard is when your love-flow's not working, when you don't like who you are, and when you can't communicate, so you're blocked in what you can do.

That's probably the best working definition of mental retardation I've ever heard. Some days I spend fifty percent of my time feeling that way. John's story shows the way out.

FIRST WORDS USING FACILITATED COMMUNI- CATION...

"My medicine makes me sleepy."

- Christian, age 20

"My name is Joshua"

- Joshua, age 5

"The article is about melanoma cancer research at the National Institutes of Health in Washington, DC." And later, "I am unhappy. I want so many things I don't have, and don't want so many things I do have."

- Bonnie, age 30

"Ride."

- Jay, age 30

"I love you, cabbage-face."

- Amber, age 11

WHEN WE FIRST STARTED TO COMPILE THIS CATALOG, WE DID NOT INTEND TO INCLUDE REFERENCES TO SPECIFIC CLINICAL/EDUCATIONAL METHODS. AFTER ALL, THE CATALOG IS ABOUT COMMUNITY, RATHER THAN REHABILITATION, AND WE FELT THAT SPECIFIC CLINICAL METHODS (HOWEVER USEFUL) WERE ADEQUATELY COVERED BY PROFESSIONAL, ACADEMIC AND ASSOCIATION JOURNALS.

BUT SOMETIMES, A SPECIFIC TECHNIQUE IS DISCOVERED THAT HAS IMPLICATIONS FAR BEYOND CLINICAL OUTCOMES. WITH FACILITATED COMMUNICATION, CHILDREN AND ADULTS WHO HAVE BEEN LABELLED WITH AUTISM OR SEVERE COGNITIVE DISABILITIES HAVE BEGUN EXPRESSING THEIR THOUGHTS AND FEELINGS, AND REVOLUTIONIZING THEIR PARENTS', TEACHERS' AND FRIENDS' UNDERSTANDING OF WHO THEY ARE.

THE METHOD IS ENTIRELY WITHIN THE CAPABILITIES OF PARENTS, FRIENDS, TEACHERS AND TEACHING ASSISTANTS. THERE ARE SKEPTICS, BUT IT IS A RESPECTFUL, GENTLE APPROACH TO COMMUNICATION THAT IS WELL WORTH EXPLORING.

FACILITATED COMMUNICATION

Facilitated Communication is a means of 'facilitating' expression by people who either do not talk or do not talk clearly. Rosemary Crossley, educator and founder of the DEAL Communication Centre in Melbourne, Australia, is the originator of the method. She believes that for people with autism and other communication disabilities, the problem of communication may not be essentially cognitive or receptive, but is rather a difficulty with expression.

In January, 1990, Douglas Biklen, Chairperson of Special Education and Rehabilitation at Syracuse University, began to use the method in Syracuse schools and community settings with students labelled autistic, ranging in age from three years nine months to 25 years old. All of the students either do not speak or have speech comprised of echoes. Most of them had previously been presumed to have intellectual disabilities. With facilitation, these students can point to letters and thus construct words, phrases and sentences. They are producing natural language through their typing; they are showing unexpected literacy and numeracy skills. The method involves initial hand-over-hand and / or arm support, pulling the hand back after each selection, slowing down the movements, assistance in isolating the index finger, verbal reassurances and encouragement. Over time, the physical support can be faded back completely or to just a hand on the shoulder.

For a detailed description of the method, see Bicklen's article entitled "Communication Unbound: Autism and Praxis" in the August 1990 issue of the Harvard Educational Review.

For more information, and for dates and locations of workshops in the United States and Canada, contact:

Facilitated Communication Project
Syracuse University
Division of Special Education and Rehabilitation
805 South Crouse Avenue
Syracuse, New York 13244
Phone: (315) 443-9657
Fax: (315) 443-3289

SARAH WAS INTRODUCED TO FACILITATED COMMUNICATION AT AGE 17 ON OCTOBER 22, 1991. BEFORE THAT, SHE COMMUNICATED HER BASIC NEEDS THROUGH SIGNS AND GESTURES. SARAH ATTENDED A SPECIAL EDUCATION CLASS IN A REGULAR HIGH SCHOOL, AND WAS MAINSTREAMED ONLY INTO A MUSIC CLASS. BECAUSE OF SARAH'S DIFFICULTY IN CONTROLLING HER BODY MOVEMENTS AND HER LIMITED MEANS OF COMMUNICATION, HER CAPACITY AND ABILITY TO LEARN WERE GROSSLY UNDERESTIMATED. ONE OF THE FIRST SERIES OF COMMUNICATIONS FROM SARAH, WITH THE ASSISTANCE OF HER FACILITATOR TO HELP HER REDUCE HER UNCONTROLLED HAND MOVEMENTS, INCLUDED, "I CAN'T CONTROL MY BODY," "I'M NOT STUPID, DON'T TREAT ME STUPID," AND "I WANT TO GO TO A REGULAR HIGH SCHOOL."

This is a dialogue between Mom and me.

Me: I wasn't a believer in facilitated communication. I thought Joe [my speech pathologist] had lost his marbles. I knew I was intelligent, but I didn't know how it would work. It sounded far fetched. I couldn't even point to pictures. How the @#\$\$ was I gonna point to letters?

Mom: I had worked for many years to accept Sarah just as she was, and the suggestion that Sarah might

be much more capable of making choices and saying what she thought and felt was scary, thrilling and totally disorienting. I was humbled as I had never been humbled before. The only thing I thought I really know about Sarah's capabilities was levelled in one memorable day.

Me: It was strange how so many people believed in me when I didn't believe in myself. I had stopped believing in my ability to be a person. I didn't know if I could.

Mom: I was afraid to believe. I didn't want to be part of a miracle and have it fall apart. I didn't want to go backwards by hoping and being disappointed. So many times I had hung onto hope, dreams, and any chance for someone to say, "It's all been a mistake, Sarah is perfectly normal," (whatever that is). It took me quite a while to be a believer in every inch of my heart. Now I am.

Me: I don't know what made me decide to try it. I had closed myself off from what seemed to be an unfair, strange world. Now I had a chance - but I wasn't sure I wanted it. There wasn't anything to lose by trying, so I did.

Actually, I found I had a lot to lose. Now, I had to

engage my brain. I used to just be, now I had to become.

At first I couldn't even think of how to start. Then I knew, but didn't know if I could. I started and it just came out. It was - so weird.

Why I ever stopped trying before, I don't know. I don't think I consciously chose to stop - it just happened.

Mom: Sarah, it's very important to me that I support your choices for your own life now, and sometimes I make decisions for you instead of remembering that this is your life and I don't have to do that anymore. I have always learned a lot from you, when you were just being. Now the lessons are fast and frequent, yet I wouldn't trade away this experience for any other one.

Me: I'm glad that I decided to try and become. I wouldn't go back for anything. I think it's important to say that if I was to give advice to somebody who has given up, I would say that it's not worth it to give up. I did, and I regret it. Now that I try, it's amazing what I can do. Maybe "Yale."

"They don't suffer; they can't even speak English."

-George Baer, 1902, on the United Mine Workers

For the handicapped person who has felt abandoned, there is only one reality that will bring him back to life: an authentic, tender and faithful relationship. He must discover that he is loved and important to someone. Only then will he discover that he is worthwhile; only then will his confusion turn into peace. And to love is not to do something for someone; it is to be with him. It is to rejoice in his presence; it is to give him confidence in the value of his being.

- Jean Vanier

A Man Without Words

A Man Without Words,
Susan Schaller; year; 203
pp.; \$17.95 from: Summit
Books

The Boston Globe (Monday, February 4, 1991 page 29 et. al.) reports on a book by Susan Schaller, who volunteered as part-time interpreter of American Sign Language (ASL), and her journey with Ildefonso, a 27 year old undocumented Mexican man who was not only deaf but also without language.

She met Ildefonso in a class of students who were deaf, but received no encouragement, material aids or supervision to teach him to sign. Using ingenious mimed demonstrations,

over and over again, she finally broke through. As suddenly as he discovered the communion of minds, Ildefonso "could see the prison where he had existed alone, shut out of the human race for 27 years". Ildefonso did not even know he had a name.

After he gained the power of sign language, he told Schaller about how, as a child he begged his father fruitlessly in mime to let him go to school like other children. He knew he was deprived - of what he knew not.

A Man Without Words is a manifestation that people who gather for connection with one another, and who persevere, can bridge gulfs that seem impassable.

- ED PRENET

I Raise My Eyes to Say Yes



I Raise My Eyes to Say Yes,
Ruth Seinkiewicz-Mercer and
Steven B. Kaplan; 1989;
\$17.95 from: Houghton Mifflin
Co., 2 Park Street, Boston,
MA 02108

The literature about people with disabilities has been on the whole written by others. This book is an attempt to convey the story of a woman with severe disabilities and her journey from her home to the institution and back into the community — as she saw the process.

It is a moving story of the hardships of family life for a child with a disability, the massive torments of institutional living, the strengths and

weaknesses of personal struggle, and the high and low points of human beings along the way.

Ruth's story ultimately is a happy one with the launching of a new and very different life outside Belchertown State School. Nonetheless, it is important to attentively read this too-rare first person view of the ways in which people's lives are shaped by those around them. With all the hopes now being placed in "community" it is a good caution to remember the human beings who are reliant on it, and to be and do the right thing.

- MICHAEL KENDRICK

This book is essential reading for every worker, planner and administrator in human services.

-DW

?

Despite my unavoidable dependency on others for physical assistance, I am a very independent person in thought and spirit. I have always striven to be as self-reliant as possible.... Without a doubt, my inability to speak has been the single most devastating aspect of my handicap. If I were granted one wish and one wish only, I would not hesitate for an instant to request that I be able to talk, if only for one day, or even one hour.

.THERESA.EYES.UP.SAY.YES

We knew what it was like to be unable to express even one thousandth of the thoughts whirling inside our minds... and what it was like to live on Ward 4 of the Infirmary of Belchertown State School in 1962.

As our mutual recognition of that knowledge emerged, our souls embraced. Our eyes locked for several exhilarating, magnetic, timeless moments.... I responded with loving sounds of my own, and raised my eyes in an emphatic "Yes!".... At that instant Theresa figured out what none of the staff would decipher for several years: that I raised my eyes to say yes.

I find hope in her anger, her outrage. Others might call it aggression and make plans to "decrease the maladaptives". I call it hope. It is a sign that she hasn't given up on herself. I love her. I love all the people who are still struggling. They still have hope.

- Kathleen O'Kelly

On Gifts and Giftedness

BY REGINA DEMARASSE

Editor's note: Regina DeMarasse spent her first eighteen years as a gifted arts student in New York City, working in theatre, music, dance, even building hammer dulcimers. She was in her first year at university when a spinal tumor flared into action, first taking her mobility, moving on to quadriplegia, and finally taking her sight. She moved to a Rehabilitation Center (read nursing home) in Connecticut, and fully expected to spend the rest of her life there.

In 1988, George Ducharme, Pat Beeman and Beth Mount met Regina. Together, they gathered a circle of friends which became so committed to Regina's vision of a different future that they invented a way (some say they moved Heaven and Earth) to move her out of the rehabilitation center.

Today, Regina shares her life with a family in Wolcott, Connecticut. She manages her own system of personal assistants, travels, writes with a computer operated by Morse code, is a dynamic speaker, an insightful advisor, and a tireless advocate. When George Ducharme asked her to do some writing for the Catalog, she replied with the following observations:

On Gifts and Giftedness

Garrison Keillor once did a wonderful, wonderful monologue that made me cry a considerable lot [Waiting for the Bus, in the Gospel Birds album]. He told about waiting for a bus and a

having a group of people with mental retardation come along to wait for the bus with him. At first he felt uncomfortable about it and edged away. Then he recognized one of the young men as someone he had grown up with. Garrison thought back, and couldn't remember his friend as someone with a disability... this fellow was just another kid back then... maybe a bit nicer. They'd played Cowboys and Indians, visited each others' houses, connived together, and then their lives went separate ways. Garrison felt that his friend wouldn't remember him, and didn't try to make a connection, but for those few moments at the bus stop, he allowed himself to feel an affinity with these fun-loving, playing, clowning "children of God." And realized that he, himself, was just another child.

Garrison Keillor talks a lot about shyness and people apologizing for their existence. He once made the statement that if you're alive and breathing, there must be reason for it in God's Divine Plan. Boy, did I ever need to hear that!

Bethany's Gift

As I write this, I'm thinking about a little lady I live with. She giggles a lot: at me, when I roll in the door, at Jeanne, at her Mommy and

Daddy, practically anyone. She laughs at her triumphs and crawling excursions, at other people's laughter, any number of things. She reminds me that I need to laugh more at myself and at life, that there's hidden delight and humor everywhere if I would only open my eyes (mentally) and "be ye like little children". So I, too, may enter the Kingdom of God. That's Bethany's gift.

Lisa's Gift

Lisa, my old roommate, was once diagnosed as having borderline mental retardation. I never knew that for a long time. I did know, however, that she was quite a loving person and, somehow, seeing her love and gentleness towards others (some of whom were scary to full grown adults with higher I.Q.'s), I learned to view people with more love and gentleness.

Honestly, George, when do I not receive some gift from anyone I know? I often forget this point, so thank you for asking me to write this. I need to stop and consider these matters more... what can I learn from this person, these circumstances? What can be created here? What's waiting to be born?

Once I didn't think I was likely to work well with people with mental retardation — not that I'd do badly,

but I thought I wouldn't get much gratification from them since I had this idea that I'm a literary/intellectual type. Then I met a number of people at Whitewood who taught me to see things with my heart. The more you learn intellectually, the more you think you need to learn, but when you learn with your heart, you're filled. Lisa, Suzie, and Denise taught me how to get filled.

If people would just learn to listen not only with their heads and intellects, but with their hearts, their nerves and the part of them that feels, if people would learn to listen with their sense of humor, their sense of awe and the child within them — they'd see for themselves, they'd hear for themselves, and, who knows, they might even then be able to *think* for themselves!

Denise's Gift

"Aaaaaw right!", Denise agreed, physically able to speak, but not always remembering how. Nonetheless, she was always able to tell you loudly and enthusiastically when she shared a sentiment, especially about men. "Aaaaaw right" was her favorite phrase.

Interestingly, Denise could remember all the words to popular songs on the radio — as long as she could sing them. In later

years, she got a communication board like Laura's and was able to point to letters of words she couldn't think to say. Denise also had the loudest, most robust laugh I've ever known, ending in a shriek. When you'd tell her, "Denise, you're hurting my ears," she'd laugh all the merrier. She also had incredible patience and could sit stroking your hair or massaging your neck and shoulder

A black rectangular box containing white text that reads: "The more you learn intellectually, the more you think you need to learn, but when you learn with your heart, you're filled."

for an hour or more. If I was sitting idly in the hall, or just about anywhere, and felt a tickle at my hair roots or the kneading of my shoulder, I'd say, "Denise?"

Mitch's Gift

He talked about Zen Buddhism, the Tao, the Bhagavad-Gita; all of which I had heard about, or read

about, but of which I had little understanding. Mitch showed me that I had experienced these states in my own life without ever giving them a name. When I look back, I see that I had Zen experiences when I'd "let go", when I was "present", appreciating the moment unclouded by labels, categories and prejudices of the past. It happened when I would "go with the flow", accepting people and circumstances as they were. Mostly, however, I fought against it, wanting to be somewhere else. At that time I wanted to be in some other condition, beyond my illness and everything it seemed to mean — all the limitations I thought it imposed. I would come to learn with the help of Mitch and others, how to let go.

In later years, I kept Mitch's lesson in mind, wondering what God intended me to learn from this illness. My friend Ray Quinn has often suggested that in my prayers I ask God, "What is it I am to learn?" The answer continually reveals itself as I learn empathy, compassion, understanding and trust through my circumstances. I have learned so much, so I can be more giving. The teacher has always been before me, in the people I meet, in circumstances that are beyond my control, and within myself.

Remember:

HEALING

*I am not a mechanism, an assembly of various sections. And it
is not because the mechanism is working wrongly
that I am ill. I am ill because of wounds to the
soul, to the deep emotional
self and the wounds to the soul can take a
long, long time, only
time can help
and patience, and a certain difficult repentance long, difficult
repentance, realization of life's mistake, and
the freeing oneself
from the endless repetition of the mistake which
mankind at large has chosen to sanctify.*

- D.H. Lawrence

*....my fears are your fears, old fears ... of want and loneliness,
of unknown tomorrow.
Of such death as war and lynchers bring,
of hate often taught and intolerance bequeathed and legislated —*

*my needs are your needs, old needs ... of bread and love,
of work and peace,
of room to grow, and time to think, and long years to live.*

*I fail where you fail, seek what you would find ... question what
you would have answered —*

*- Walter Benton,
Never a Greater Need*

2.

Re-Visioning Community

*Community is not
an abstract ideal, but
a concrete expression
of personal commit-
ment. It is a witness
to the essential unity
of the human family.*

- Faye Svingen

Last winter, I had the privilege of attending a Native traditional community dance. There was pride, and laughter; there were contests and honors, music, and family, and friends. And then there was silence as one of the elders announced that the community had a special reason for celebrating this particular evening. His nephew, a young man who had always had a major place in the Dance, was returning to the Circle of the community. His words, while respectful, conveyed the truth that the young man had left the Circle in rebellion, and had struggled with alcohol, and isolation. Now, he had made a decision to return.

The Uncle and another elder welcomed the young man into the Circle to the applause of the people gathered there. They covered his shoulders with a ceremonial robe, and flanking him, walked a full turn around the Circle, while the singers and drummers chanted a welcoming song. The trio stopped for a long moment, and then, one by one, every person attending entered the circle in a double line, facing the young man. As they danced, every single member of the community - children, teenagers, grandmothers, elders, parents - took his hand, touched him, embraced him, and welcomed him back.

When the Uncle made his announcement, he said that while the young man was away from the Dance, that the Circle of the community was broken. Now that his nephew had returned, the Circle was being made whole. There was joy because of the healing of the young man's life, but the big celebration was because the community itself was being healed! Later that evening, I thought about other people who have been lost to the community, and what it would mean to them to hear that the Circle is incomplete without them, that the community needs them — and that they will be received with joy when they return.

- DAVID WETHEROW

*We must delight
in each other, make
others' conditions
our own, rejoice
together, mourn
together, labor and
suffer together, al-
ways having before
our own eyes our
community as mem-
bers of the same body.*
- John Winthrop, 1630

For decades, families have been taught that the most important job they can do on behalf of their sons and daughters with disabilities is to work on the "boundary" between the family and the service system. Over time, they become convinced in that the community is fundamentally inhospitable and that it lacks the willingness and the capacity to include and support people with disabilities. They come to believe that the only source for secure futures for their sons and daughters are the formal structure of government and professionalized services - and then only if they, as parents, put in enough effort.

Most often, when we talk about advocacy, or "self-advocacy," or "partnership," or "consumer participation," we are talking about interactions on the boundary with the formal system, rather than with friends and neighbors and the broader community. In the long run, the community comes to be seen as little more than the stage setting where formal services occur.

Reconnecting with the power and commitment of the community must begin with seeing community in different terms. Now, writers like John McKnight are providing the ideas and the language that can allow us to re-envision community as capable and hospitable, and to help families and friends invite the community back into relationship with vulnerable people.

The beauty of beginning to think as John McKnight and others have challenged us to do is that we do not have to invent new methods, find new technologies, or look at recent innovative literature to discover community. What we need to do is open the window and look around us to listen, to learn, to experience and to understand the lessons being taught daily in large kitchens, in small living rooms, in church basements and on neighborhood street corners.

The good news is that there are centuries of experience concerning communities of people living together - lessons written, spoken, sung and transmitted from one generation to the next in every country and village on this earth. Community grows out of *story* — not data; it is an expression of a common tradition. Our challenge is to collect as many examples and stories as we can concerning people living together in community, working out the tensions between commonality and diversity, re-generating community when it has been lost, and celebrating its rediscovery.

- GEORGE DUCHARME

A TALE OF Two BRIDGES

- BY JACK YATES

The railroad bridge across the St. Lawrence River at Quebec City, when it was built in the early twentieth century, was the longest cantilever bridge in the world (that's the type of bridge formed from a complicated series of triangular steel girders, a big black framework above the road-bed). Remarkably, an early moving picture was taken of stages in its construction, and by chance the movie was being filmed as the bridge collapsed into the St. Lawrence, with the loss of life of dozens of ironworkers. In the movie it can be seen that the bridge was being built out from one pier or support, all the way across the river, to reach the opposite pier. The builders started from one side and had gotten more than halfway across to the other when the bridge collapsed. The bridge was rebuilt, lessons were learned, and it still carries the railroad across the wide river.

The original bridge across the Niagara Gorge, built about 1848 by Charles

Ellet and John Roebling, is of an entirely different design. It is a suspension bridge, the archetypal style of bridge design with the sweeping curve of cable above the roadbed, the cable hung from two high supports, the roadbed hung from that cable. The Niagara bridge, built to carry the railroad between Canada and the US, was one of the first major suspension bridges, and the challenge of construction at that site made it a model with world-wide impact.

The biggest challenge was to get the cable, which would support the weight, across the gorge. In building a suspension bridge, that's the first step in linking two sides. To build the Brooklyn Bridge, for instance, the first thing Roebling had to do after the two support towers were underway, was to get the cable across the river. With the Brooklyn Bridge that was easy: carry it on the ferry. But with the Niagara bridge, given the steep cliffs and the swirling waters, a boat could not carry the cable. It was this challenge which led many engineers to doubt whether such a bridge could be built.

Ellet solved the problem in this way: he held a kite-flying contest. The winner, a boy from Niagara Falls, Ontario, won the opportunity to fly a kite one windy day across the gorge on a long,

silk thread. On a windy enough day, that part was easy; the real skill came then in getting the kite to come down into the arms of Ellet and his colleagues who were waiting in Niagara Falls New York. The work crew in New York then tied a single strand of steel wire to the twine, signalled, and saw the wire pulled back across; and the process was repeated over several times until that silk thread had become a steel cable strong enough to carry the roadbed and two railroad lines across the Niagara Gorge.

Many of us who serve people who have been segregated and isolated see that there has been created a gulf between our service systems' inhabitants and their communities, so we have seen that a major part of our jobs must be building bridges across that chasm. Our work, in other words, is civil engineering. With that mission, we need also to remember that it may be ineffective, perhaps even foolish, to try to build only from one side of the river toward the other. We will need to build supports on both sides, to recruit people on the other side who are willing to catch the kites we fly, and to know that where the chasm is deep and waters turbulent, we can only work toward trainloads of people by beginning with an individual thread of connection.

Community Dreams



Someone decides to start a bank of dreams. He thinks

what's needed is some way to convert low-voltage good will into high-voltage action. He will be a transformer, a currency converter. He will track down small-scale, local-level, non-technical, low-cost community ideas from his imagination and his experience, and from his friends and from around the country, and deposit them into a bank of vignettes, fragments, thought-starters, sparks. Then he'll open for business. Anyone can take out loans or make withdrawals. The idea is to give all his assets away.

Community Dreams is a unique and far-reaching compilation of ideas for

1
enriching neighborhood and community life. The ideas here are fresh and offbeat, small in scale and low in cost. They are ideas for practical use, by people like us, close to home.

In Community Dreams you'll find town-owned bicycle fleets, solar barn-raisings, neighborhood yearbooks, the Al Fresco Branch Library. Hundreds of creative new and borrowed ideas, like shopping mall ministries, edible landscapes, and universities of the sidewalk.

Read and dream about street life, arts, housing, energy, trash, parks, media, food, skills, neighborhoods,

urban design, health, government, safety, workplaces, festivals.



When an elderly neighbor broke a hip and needed to recuperate at home, neighbors took turns living at her house a few days at a time. They exchanged not just their services, but their whole selves.



Ten in the morning on a side street in town. New buildings going up. A bricklayer, working with mortar and trowel, putting up a side wall.

A small crowd gathers, a blend of men and women, young and old. The bricklayer turns:

"Now, when you're putting up a wall like this, what you want to do is to make sure that.... You start by.... And when you've got that lined up, then you...."

This is the Tuesday morning bricklaying lesson, brought to you courtesy of your local construction company.



Another group of kids, early teens mostly, wanted their own space to hang out (nowhere to go in town). They took a construction course and went together to builder's camp for a month one summer. On their re-

turn, they built their own youth center, by themselves, under direction, board by board.

Berkowitz ends his book with an invitation:

You have read about my dreams: I would like to read about yours.

Across America, I believe there are thousands of community ideas like those mentioned here, but different and often better. Yet many ideas of them are secreted, forgotten, half buried and left for dead. They don't get publicized because their creators are not writers and because they wouldn't know how or where to publicize them outside of their own communities. There's also no incentive for doing so. How can we provide one?

I envision a sequel to this book, richer and more exciting than this one, of community dreams and real community actions of your own. I see a network of dreamers from coast to coast. I'd like to find a place for regular publication of new community ideas as they are thought up and implemented. We can start right here.

So I ask you to send me your dreams and your realities, in a paragraph or two or more, in whatever form makes most sense for you. What new ideas have worked in your community? What

could work if given a chance? Be fanciful, or specific; let your mind run free.

All replies will be acknowledged. If there are enough, I will try to arrange for their publication, with proper credit to contributors. If you take a step, a bank of dreams may be closer than we think.

Address your response to:

Community Dreams
Impact Publishers Post
Office Box 1094 San Luis
Obispo, California 93406

"Material skills have for so long been accepted as merely the purchased property of corporations and the state that seeing them as the ordinary skills of ordinary people in ordinary settings may seem novel or even unsettling."

*Karl Hess, quoted
in Community
Dreams*

On Fallibility

We can commit ourselves fully to anything - a marriage, a place, a discipline, a life's work, a child, a community, a friend, a faith - only in a poverty of knowledge, an ignorance of result, a self-subordination, and a final forsaking of other possibilities.

- Wendell Berry
Standing by Words

We must delight in each other, make others conditions our own, rejoice together, mourn together, labor and suffer together, always having before our eyes our community as members of the same body.

- John Winthrop, 1630

John McKnight spoke in Holyoke of the dangers of utopianism, of the belief that perfection should be sought by control, through systems and institutions and societies. He suggested that instead of "control, so things will go right," our goal should be the place where "fallibility reigns" — the community, "the spaces in society where we know things won't go right." McKnight said that "community is the sum of our fallibilities, our capacities, and our possibilities," rather than of our deficiencies and our perfectibilities. In community "there are no people who are handicapped, there are only fallible people, and their fallibilities vary." Our goal should not be community itself.

Some of our temptation to romanticize community may come from sort of an unconscious drive or wish to "fix" things. I think normalization-oriented people are unlikely to want to "fix" the person with an impairment; we understand that this line of thinking is at best futile and at worst a form of blaming the victim. But we may be prey to setting as our goal the "fixing" of the situation around the person. Institutions were a bad approach, so we hoped that deinstitutionalization and group homes would "fix" the situation. We found that congregated

settings like sheltered workshops were futile, so we hoped that de-congregation of programs would "fix" the situation. Now we find that better program models have not "fixed" loneliness, so we hope that friends and associational membership will. We will find now that friends, associations, and community will not "fix" the situation either. The problem is that *life* cannot be cured; the community is fallible. And we need to remember that community, like other things we have been tempted to romanticize, cannot be judged by whether it "fixes" people or situations; like de-congregation and like associations and like friends, and maybe like life, community is worthwhile for other reasons.

So if community isn't Utopia and won't fix people and won't resolve people's situation in life, then what is it good for? To paraphrase John McKnight, it's the only remaining uncontrolled space, the only place you can sing together and the only place you can die together. It's the only place we can never abolish suffering, and the only place we can never abolish joy. The fallible community.

JACK YATES

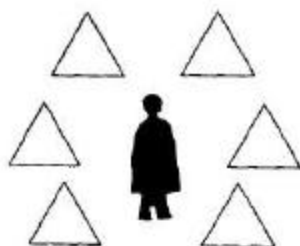


Traditionally
...a promise (a vow)
...naming, name-sharing
...a ceremony involving
the larger community

Always
...shared social status
...shared resources
...unconditionality



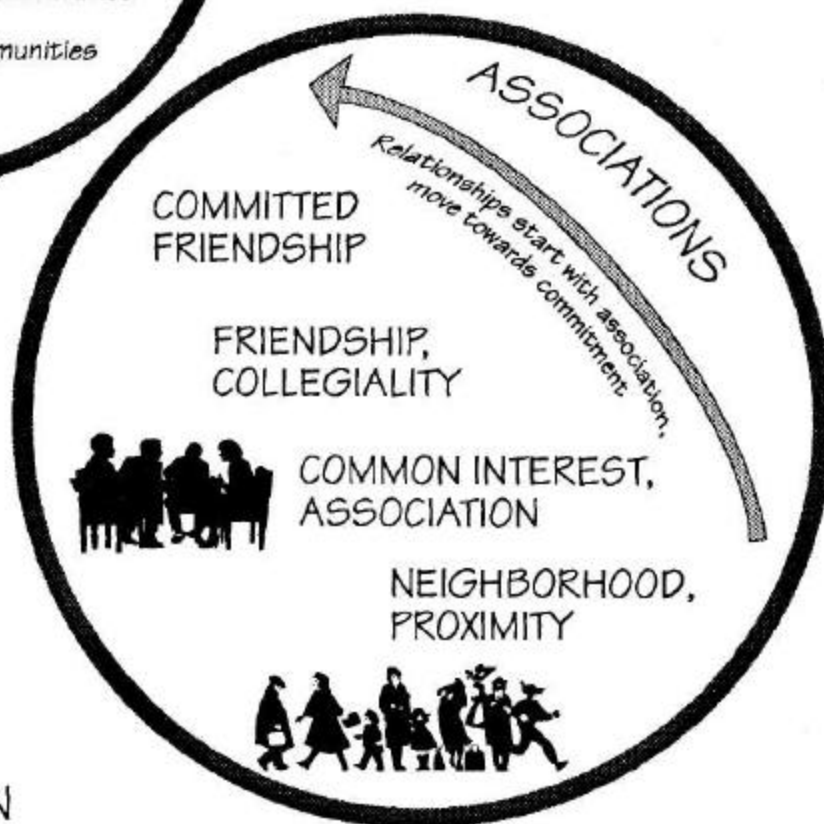
ISOLATION



ISOLATION,
surrounded by services

A Map of Relationships in Community

(Where do you want to live?)



Twelve Weeks in Spring



"In the process of caring for Margaret, we strangers had bonded. We have a unique knowledge of one another. It is founded on rock. All our lives, we'll trust each other."

Twelve Weeks in Spring:
The Inspiring Story of Margaret and Her Team, June Callwood; 1986; 312 pp.;
\$14.95 CDN from: Key Porter Books, 2775 Matheson Boulevard East, Mississauga, Ontario L4W 4P7

Twelve Weeks in Spring tells the story of a circle of sixty people who gathered to help Margaret Frazer, a good friend, stay in her own home, out of hospital, and in loving arms during her final and terrible struggle with cancer. This book makes it clear that heroic action is within the capacity of perfectly ordinary people. It reminds us of the quiet heroism occurring every day in our families, churches, and neighborhoods.

The book also contains the seed of the next challenge. The next step taken by some of Margaret's friends is a curiously reversed image of what they had shared together. In their compassion for people who are dying of AIDS, and without friends, they begin work on a "hospice" residence, complete with board of directors, paid staff, and government funding.

What kind of community response would reduce the need for such institutional solutions? How might we support and encourage friends, neighbors, or members of congregations to offer this care? How do we break down the barriers of fear in our own hearts? June Callwood

offers a profound gift by recording this experience, and sharing images of what is possible. Sooner or later, the questions facing Margaret and her team become our questions. Here are some of the answers.

After Margaret Frazer died, a newspaper account described how some sixty friends formed a team to stay with her around the clock for three months so that she could die at home.... One of the wonders of human nature is that most people are capable of fine behavior in an emergency... people respond in a time of peril with a strength they never knew before and are grateful to find that splendid self within.

No one talked any more about whether helping Margaret stay in her home was a mistake. Clearly, she was rejoicing in the sight of spring coming to her garden, the hours of listening to Glenn Gould play Bach, the morning meditation in the lovely old rocker in her study, climbing into her own bed at night.

?

Every conversation with Margaret had a quality of reflection. When she asked what we were doing these days - and she always did - we replied by putting our

activities in a context to avoid the suggestion of purposelessness. In Margaret's presence, it would have been blasphemy to speak of time frittered, mobility unappreciated, or energy used thoughtlessly.

In telling her of ourselves, we learned who we were. We saw the patterns.... she paid us close attention, which is rare enough in most social exchanges. She gave us back a better self; she always saw us as wiser, more sensible, more gifted, and more generous than we are.

We who loved Margaret — and everyone here did — were privileged to be part of the team that tended her these past few months. We have memories that we'll cherish all our lives of her courage, and her grace, and her will, and her intelligence, and her connectedness to us despite the vagaries of her illness. *She made us a gift of our giving*, which is quite an extraordinary accomplishment.

We had the redemptive experience of being part of a human tribe functioning at its best. We don't have her any more, but we do have our better selves, we have a better sense of the safety of our community. This time the centre held.

Caring for just one beloved and fragile old body seemed - well, self-indulgent. Luxurious. Anti-social, maybe....

In February, my friends and co-workers and family came together in graced solidarity, so that at last I was able to hear "Yes, you may". New Times staffers, no strangers to emergency, said that I should feel free and that they would cope with my sudden exit. A friend who carried in her life the burden of wealth, solved, at a stroke the financial difficulties posed by my joblessness... Close friends came even closer. Our whole support network followed my mother and me with their hearts.

It is satisfying past words to close the life-cycle with someone you love deeply. My mother was very weak, and getting smaller and lighter all the time. By April, I could easily carry her in my arms from one place to another. She needed to be bathed, and fed liquids ounce by careful ounce.

Of course it is no news that the greatest human tenderness is evoked by the weakness of someone we love.... When the weakness is in one's own mother or father, there is more than the familiar tenderness. There is a profound experience of justice. This delicate body needing to be cleansed and tended belongs to the one who tended me, night and day, in infancy. Everything I do for her now, I needed from her then. And she gave it with delight. I return it, and find delight. It is a fair exchange. The fairest.

*-from Janet Somerville,
Flight of a Marvellous Soul: An Advent Meditation,
Canada Lutheran, December, 1984*

They Came for Merilee

Sharon Gretz, a friend in Pennsylvania, had a friend named Merilee who had lived in a nursing home for twenty-seven years. In her fight to gain her freedom, she became the spokesperson for a large "class" of other young people who wished to move to the community.

Several years after leaving the nursing home, Merilee was diagnosed as having terminal cancer. From a "system" perspective, her illness raised her "level of care" beyond allowable limits, and a struggle began to help her remain in the community. Sharon was part of that struggle, but it was clear that she and Merilee needed more support if they were going to be successful.

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November 14, 1990

Dear David:

Thank you so much for the copy of Twelve Weeks in Spring. It was incredible, and I learned so much through Margaret Frazer's story. I struggled for a long time about what to do about Merilee's situation, and the story of Margaret opened up a lot of my imagination about what could be possible. Over the summer, Merilee and I spent a lot of time together. I learned so much from her of her hopes, her fears, and the dreams she still holds. After a month or so, I suggested that perhaps the members of her new church might want to hear from her about what is going on, what she has been dealing with, and what she was thinking about for her future....

During this whole thing, my biggest fear was that someone would decide she needed to return to the nursing home. That was my nightmare. But Merilee's most pressing concerns were different. She worried about going back and even said that she would surely die if this happened, but there were other things on her mind that took precedence. Things like having something to do instead of having her life on hold. Seeing people, making friends. Having a way to help other people. Like knowing where she was going to live (she had to move in the midst of all of this.)

.....

I talked through this with Pat Beeman and George Ducharme in Connecticut. Pat advised me not to wait to call her church members together, since there were things they could be doing to make her period of treatments more comfortable. Also, talking through it helped me realize that I could not begin with her church by asking them to defend her life and to fight off any attempts to send her back. It seemed that the first order of business was to simply bring them into the loop about what had been going on and why they had not seen her much in the last few months.

I got the names of people from Merilee whom she wanted to invite to gather together with her. There were just two names from the church, and the rest of her self-ascribed friends were UCP [United Cerebral Palsy] staff of some sort or another. David, I seriously prayed that night that people would come. Merilee almost called it off because she had been let down before, and she was sure no one would come. Yet when we sat at the parlor at Linway church waiting that night, wouldn't you know that people started to come. The marvelous thing was that there were three of us from UCP, her Mom and Dad, and ten people from Linway Church! Somehow word had gotten out that we were gathering that night, and people came to find out more about this woman who had been missing lately.

There was a lot shared that evening; primarily Merilee shared herself with us. I struggled with my role in being there, but somehow it just came to me that the greatest thing to come out of it would be for people to come to know her in a deeper way.... People shared different experiences of wondering about Merilee. Now she was here before them and spoke freely about her cancer, her life circumstances, the years in the institution, how much she wanted to contribute and help out at the church. She was witty and charming and had worn a lovely dress, and had her hair done. When the evening was over, she was so happy. She said to me, "They really want me here! Sharon, THEY CAME FOR ME. That makes me happy. I have new friends."

As things turn out, Merilee has become very much involved in the life at Linway. Yet I still was not seeing the people of Linway becoming involved in her home life. I was hoping that there would be come for it to happen on its own through a growing relationship together, but as it turns out, Merilee has learned that the cancer is growing again and it is likely that she will need radiation therapy. The doctor has told us that anyone with thoughts that it will go away is wrong, barring a miraculous cure. She really doesn't want to think about that right now, and we are respecting how she wishes to handle what is happening to her.

Going through more treatments means that she will need more support at home. Our Executive Director is in quite a quandary, as the amount of help she needs has escalated, yet the amount the county and state give us to pay her helpers has stayed the same. Creative bookkeeping has helped, but he can't go on like this much longer. I thought that we could again go to the people at Linway and ask them to help. Since they weren't on their own recognizing her need to have them involved at home, I decided to leave behind the subtle and gentle approach and adopt some sort of style more akin to the Georgia approach to Citizen Advocacy. Translated, this means that what I did was I went to the pastor and said something like, "Look, she's one of you. She's one of your own and she needs you, and she needs you now. Your congregation has got to do something or she will be incarcerated again and that will be the end of her. We need people and we need money. Here's why. Now, how do we get this going?" I actually was not as harsh as it sounds, but I pretty much just dropped the situation in his lap and said, "What are you going to do?"

Pastor Ed was great. He's a sixties child, now a minister, and the kind of person who says and thinks good stuff about the notion of inclusive community. After asking a lot of questions, he finally announced, "So, what you're saying is that the biggest thing we could do for her is to give her our time. Well, if we can't do that then we aren't a very good example of a faith community. Anyway, I've been looking for a way to stir up a sense of mission. Seems to me Merilee is giving us the opportunity to find out what we are here for and what we should be for each other. Let's do it."

From there, Ed ran with it. He called everyone together, this time without Merilee. He said to them that her condition was changing again, and that she needed them to get involved to keep her safe at home for as long as we could. He pulled out a chart with days of the week and times on it, and said that he wanted everyone to consider the time that they could put in, the day, etc., and to put their name on the paper.

Inevitably, of course, someone said to me, "Ma'm, are you sure you really want us? I mean we aren't trained or anything. Are you sure we can do it? Maybe you'd rather us give you the money instead." The Ed said that part of what was happening was that Merilee is constantly surrounded by people who are paid to spend time with her, and that we needed to show her that people are going to be with her in this thing because they *choose* to be. Besides, he said, all you have to know is how to cook or clean or do laundry or read or just talk, and surely everyone in the room knew how to do at least one of those things.

So, it's started. I feel privileged to be a part of it. After the "business" of the meeting was over, people started to tell little discoveries they had made about Merilee since our first gathering. They were insignificant little things like knowing she likes popcorn, knowing just where to place her hymn book so she can use it, comments on her terrific memory, knowing her love of shopping excursions. They had been learning in small ways just who she is and had been watching to see what they should learn. The smallness of these discoveries made them all the more special, for they had come only by *being with* her.

As we proceed, I worry that the system is going to make things hard for her church friends, in the sense of creating obstacles or systems problems, etc. I am doing what I can to safeguard this.

Time's run out. Miss talking with you. Surely, one day we will meet again.

Warmly,
Sharon

August 5, 1991

Dear David:

.... I wanted you to know that my friend Merilee died in June. It was kind of sudden and unexpected, in that she had been having a good week. David, she never went back to the nursing home. This was her greatest hope, and thanks to the commitment of her friends, family and staff, she was with us to the end. We are all proud that we actually did this, and thankful for the ways that we got closer to her and for the opportunity to spend time with her and care for her. A lot is to be said for the church group from Linway Church. They were so faithful. The same for the staff from UCP. In the beginning they were sure they could not do it, but she taught them a lot about their own abilities and capacities to stand by faithfully in the most difficult of times. Her death was very hard on them, as she had become a focus in all of our lives.

You and I find these stories of people in the community incredible and fascinating. However, in this story, what I also came to see as incredible was the devotion of the staff. I have never before been a witness to this kind of care. The staff and their leaders, Mary and Ellen, made a deep commitment to Merilee. It wouldn't have happened without them. Each day, every day, they were there for her. They were true heroes.

We were gifts for her and she was a gift for us. An ordinary lady, Merilee, leaving us a lifetime of extraordinary gifts, gifts that we can multiply and share with others, if we choose to remember.

My best,
Sharon

Yesterday when I was in the emergency room, I could feel God all around me. The treatments hurt a little bit, but I'm sure without His help, it would have hurt a lot more. Since I got ill, I really see things differently. I used to take people for granted, but no more. God gave me the opportunity to be down here, but God could do everything if you let him! I think I am here to tell people don't be afraid of any sickness... especially cancer. I don't know how long I have on this Earth, but I am going to pass the word around about the Lord. I don't have children, but I want people to remember me as loving and giving. I want people to remember the new Merilee. The old one was selfish, but I don't think the new one is.

MERILEE T., MAY 6, 1991

The Syracuse Commu- nity Choir

BY BONNIE SCHOULTZ,
SYRACUSE UNIVERSITY
CENTER ON HUMAN POLICY

The Syracuse Community Choir is a group of people who gather to sing songs of peace and social justice. They rehearse weekly, and perform several times a year at concerts and "alternative" community events such as peace rallies, vigils, and benefits.

The membership of the choir includes a wide variety of people of varying ages, racial and ethnic backgrounds, and abilities. It also includes some people with visual impairments, some with physical impairments, and some who are labeled mentally ill or mentally retarded. What brings all of the members together is their interest in music as well as their desire to sing about current social issues.

The involvement of a diversity of people in this choir, including a few members with severe and multiple impairments, is made possible by a number of factors. First, the founder and director, Karen Mihalyi, has a vision for the choir as one of "inclusive community." She traces this, in part, to her childhood in a small town where everyone was part of the community. She comments, "This does not mean that there was no prejudice... but at least people met up with each other." She adds, "To create community today is difficult - so many forces work against it -but people are hungry for community."

Second, the diversity of the choir is intentional, not accidental. It happens as the result of a few things: 1) intentionally inviting a diversity of people to join the group; 2) making rehearsal and concert space accessible to a diversity of people (eliminating or decreasing physical barriers; making music and other information available in Braille, etc.); and 3) creating a welcoming environment, where people feel comfortable and know that their presence is valued.

Third, there is the realization that connections between people who have had significantly different life experiences do not necessarily occur quickly. Over time, however, opportunities to be together and share experiences help people to get to know one another on a personal level, and to both see commonalities and appreciate differences. This, in turn, helps foster relationships. As Karen puts it, "Integration of people with disabilities has to do with relationships — which come from meeting each other, knowing each other, hearing each other, learning about each other... It's the same for racism, sexism... we have to be together to get to know each other."

Through its music, the choir sings about issues of peace, social justice, and equality; and through its example, the choir promotes both the vision and reality of inclusive community as a means to achieve these.

A Place On Earth

REVIEW BY JACK PEALER

Someone said to me not too long ago that it's rare to read a review of an old book. Well, this isn't exactly a review. It's more like the sharing of an appreciation. And the book isn't exactly old. It's Wendell Berry's novel A Place On Earth, which was originally published in 1967 and then revised and re-issued in 1983 by North Point Press. It's also rare for a writer to find a publisher willing to issue a revision. Wendell Berry notes in the preface that this is an instance where "improved literary judgement can save trees." Most of his revisions were cuts from the original. I've wanted for some time to write something about this book, so here's a brief essay about a novel that's reached the age of twenty-one, or five, if you prefer.

A Place On Earth is, I think, a biographical sketch of a particular time in the life of a community. It's a story about people who are at home but who are living in their own awareness of how their home (their place on earth) is threatened — both by the ways they live in the place and by events happening far from that place. The story happens during World War II.

The main character is the town. There are human characters, to be sure; community doesn't exist without

people. The lives of the people in this community (Port William, Kentucky) are closely observed, treated with respect by the writer. Even the people who aren't likable are gently presented. The book is written almost entirely in the present tense, so we readers get a sense of immediacy about the events in the story. We're carried through the experience of the place and the people who live there. It's a vivid way to learn something about the nature of community.

Now, I have to be careful. I respect Wendell Berry's writing. I want neither to over-analyse nor over-interpret. Let me pose this definition, then: "community" can be defined as "people living together in a place." If that's accurate (it's certainly simple-minded enough), then A Place On Earth seems to be about the wedding of the definition's two parts (the people, the place).

It's about the importance — even the necessity — of continuity in a place to the very idea of community. The people in this book, the members of the Port William community, have an intimate knowledge of the place where they live. Of Mat Feltner, a middle-aged (I think) farmer who is a major thinker if the book's thoughts, it is noted that "...walking from death, (he) would have known in an

instant the place, the time of year, the time of day." (p. 33) There is much observation about place — observation of the weather, of the way the clouds cast shadows on the river valley, of the look and sound of rain on windows, of the still noisiness of a small town late on a spring night. As most of the people in Port William are farmers or members of families, there is much comment about their relationship to the land:

For always it was finally the land that they spoke of, fascinated as they have been all their lives by what has happened to it, their own ties to it, the wife of their race, more lovely and bountiful and kind than they have usually deserved, more demanding than they have often been able to bear. (p. 298)

But, the Port William members who populate this book are as concerned about their care for their place as they are with simple continuity in it. Mat Feltner describes to his daughter-in-law, Hannah, a conversation he had with his son (and her husband) who is missing-in-action:

And I told him that a man's life is always dealing with permanence — that the most dangerous kind of irresponsibility is

to think of your doings as temporary.... What you do on the earth, the earth makes permanent, (p. 176)

The other part of the definition of community that I proposed above - the part about "people living together" - is the other "pole" of this book. There is a tendency, among those of us who talk a lot about "community" and its attractiveness, to sound sometimes like we're describing some place where problems have vanished, where all tears have been dried. Wendell Berry doesn't make that mistake. Port William isn't a place where everybody's perfect. It's a place where people rub up against one another, and, as most of us know, there's both pleasure and pain in that. Much of the pain in these people's lives is caused by vacancy — by the fact of people who are important (to each other and to the community) becoming absent — lost. Mat Feltner's son, Virgil, is missing-in-action. Gideon and Ida Crop's daughter is lost in a sudden flood that sweeps away the bridge to their home. Each loss is like a rent in the fabric of the membership — a tear that even the finding or re-finding of some lost ones cannot fully repair:

...since Mat came to tell him that the baby

(Virgil and Hannah's daughter) was born, he has thought of the absence of Virgil. And he stays now because of that, sitting in that vacancy, though he knows he cannot fit or fill it. (p. 277)

The war and its capacity for creating lostness is like an undercurrent in the story. Reminders of it are regular — from letters to absent men, temporary soldiers, to the news on the radio, which the men in the general store card-game use as a finish to their time together each day. Virgil Feltner's "missing" status — his lostness to the community — remains throughout the book. Near the end of the book, the town's celebration (bonfire, music, whiskey) over the end of the war is set against the funeral of someone who was damaged by an earlier conflict. It's as though the joy over the end of one kind of vacancy-making has to be sobered by a sign that both finding and losing — both joy and sorrow — are essential to community. A community is people living together in a place. In Port William each member is important. No one goes unmissed.

Sometimes I want to go there.

Maybe you do, too.

On Avoiding False Hope

BY REGINA DEMARASSE
WOLCOTT,
CONNECTICUT

Create more regional directors to oversee things. Create more committees to investigate things. Create more supervisors to document things. Create more forms to fill out, more positions to fill. Create wasted potential, loss of dignity, discouragement, worry, loss of hope — but whatever you do, DON'T CREATE FALSE HOPE!! "False hope" is of paramount concern to doctors, psychologists, evaluators, physical therapists and many professionals in human services.

Did you ever hear of a self-fulfilling prophesy? It's the phenomenon by which a child in school, when told he is bright, dedicated, and bound to succeed, feels encouraged and works harder. It is the phenomenon by which workers in industry, when told they are producing a great product, feel proud, motivated and encouraged, and work even harder. It is the phenomenon by which members of a movement, when told what a wonderful future they are building, with their enthusiasm revived, their strength renewed, go forth to conquer and build still more.

It's healthy, you know. So why do we fear false hope as we fear splitting our pants in public? Why do professionals avoid it like the plague? What on earth is "false hope" anyway?

I've never heard these same professionals speak of "true hope", but it seems to me that might be its opposite. Must hope be either true or false, as on a short answer test, when you have a fifty percent chance of getting it wrong unless you studied and have previous knowledge? Doesn't hope imply something that has not yet come to pass? If it's something in the future, then how can you have previous knowledge?

Is there really something wrong with telling a despairing young person who wants to live independently out in the community — working, socializing, attending theatres, shopping, doing things most people take for granted — that such ideas are ludicrous? He's handicapped, so you don't want to give him "false hope." Should you avoid discussing with a person who resides in an institution what life could be like on the outside and what brainstorm she or others could possibly conceive? You might be offering "false hope." Should you let bright, vibrant, sensitive or just plain feeling people, worthy of dignity and love, lose all hope rather than give them "false" hope, because you assume that if you've never seen it done before, it's not a possibility

So what if you dare to dream a little, indulge in a

fantasy, if you will, and find out it doesn't work? So what if in pursuing a dream you find you keep bumping into big, sprawling, complex pillars or fall into low-lying vast caverns? The pillars might be trees branching out and flourishing in other directions and the caverns might contain precious crystals and gems. So what if you don't always succeed? Do you blame yourself for trying?

I used to be embarrassed to express my dreams and aspirations too openly. Despite the limitations of my blindness and quadriplegia, I had many ambitions that I could truly envision.

"What are you going to do about personal care attendants, about accessible housing and about all those other things you need help with?", members of the staff at the rehab center I resided in questioned. That was just it. Still, as foolish as it all sounded, I would have to find the way.

It was my good fortune that my circle of friends began meeting to address these matters. It was also fortunate that they were just as foolish as I, and that they chose to see my abilities over my disabilities. We could see that a lot of work lay ahead if we wanted to overcome the obstacles that were present in my situation. We began working on strategies.

"Circles of Friends" are not "the answer" for people living with disabilities; they are a process, a means, an approach to finding solutions or a better way. It is not without work that circles make things happen. Nonetheless, even the process proves meaningful, bringing people together and allowing each to broaden his or her horizons, exceed limitations and experiment with real life, rather than sink into the despair that occurs when a person is not permitted the dignity to try and fail. Failures are successes in learning what other strategies need to be attempted. Even more important is the need to have hope. Without it we slump into apathy and fulfill the prophesy of "never be able to..."

Most of the staff at the rehabilitation center didn't believe I could ever leave and survive outside. Indeed, without the support of the "crazy dreamers" in my circle, I wouldn't have been able to. We spent nearly a year working on a plan. I was happier than I had been the previous year when I didn't have plans to work on, not only because I had something to look forward to, but also because of the experiences I had in the planning process.

In the end, I did move out of the institution and into the community; I am living

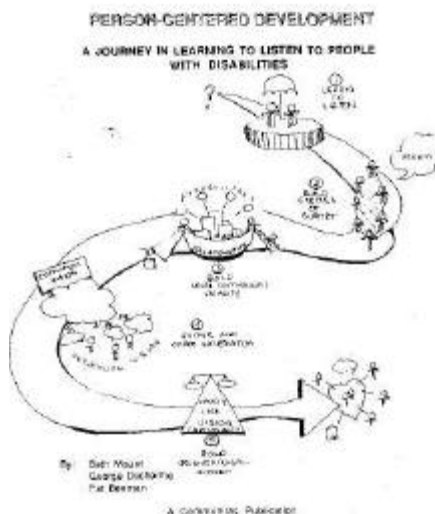
with the kind of roommates I had hoped for, in the kind of quiet, country setting I dreamed about. My time is spent writing the book I have always dreamed of, without the institution dictating where and when I could do all kinds of things I like best. I am glad that a group of us got together to share some "false hope".

There is immense hope in struggle, in suffering, in risking our securities, in standing in contradiction to the Empire. The situation is without remedy, but it is full of hope.

*Wolf
Wolfensberger*

Building Community for People with Disabilities: Person-Centered Development

REVIEWED BY JAY KLINE, NEW HAMPSHIRE INSTITUTE ON



DISABILITY

Building Community for People with Disabilities: Person-Centered Development — A Series of Six Monographs, Beth Mount, Pat Beeman, and George Ducharme;

What are We Learning About Circles of Support?: A Collection of Tools, Ideas and Reflections on Building and Facilitating Circles of Support; 1988; 30 pp.;

What are We Learning About Bridge-Building?: A Summary of a Dialogue Between People Seeking to Build Community for People with Disabilities; 1988; 21 pp.;

One Candle-Power: Building Bridges to Community Life; 1989; 45 pp.;

Imperfect Change: Embracing the Tensions of Person-Centered Work; 1990; 36 pp.;

Dare to Dream: An analysis of the Conditions Leading to Personal Change for People with Disabilities; 1991; 50 pp.;

Person-Centered Development: A Journey in Learning to Listen to People with Disabilities; 1991; 50 pp.;

\$8.00 each from: Communitas, Inc., P.O. Box 374, Manchester, CT 06040, Telephone: (203) 645-6976. You can order any three for \$20.00 the full set of six for **\$40.00**. Add \$2.00 for postage and handling for any order. For bulk orders of more than twenty five copies, contact Communitas directly.

In January, 1987, Graphic Futures and Northspring Consulting received a grant from the Connecticut Developmental Disabilities Council to work with five families in Connecticut. The purpose of this work was to help people clarify their goals, to identify obstacles and opportunities, and to bring together friends and community members to help people solve problems over time. This grant initiated the development of five circles of support.

By September, 1990, more than 50 people had started support circles with the direct support of Northspring Consulting, while an additional 15 facilitators were being trained and supported to begin 30 more support circles. These support circles are helping a number of people make dramatic changes in their lives. These individual changes sometimes lead to system change and innovation affecting hundreds, perhaps thousands, of other people with disabilities. All of

hese activities are leading us to a better understanding of the activities and investments required of person-centered change.

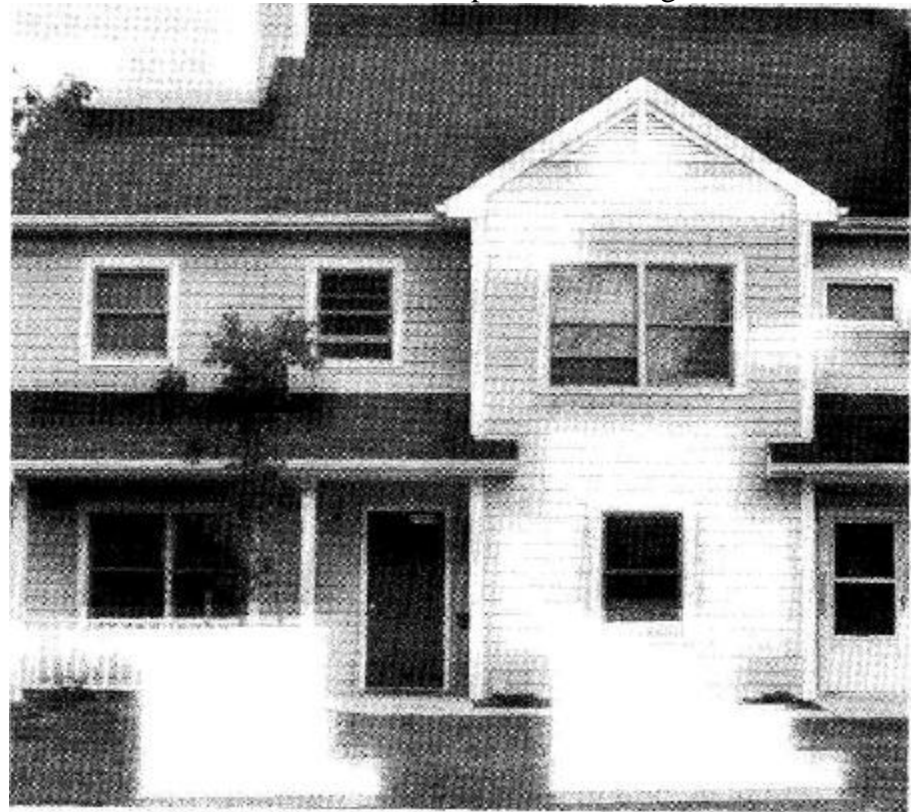
If you are thinking about, seriously considering, or preparing to develop a circle of support for yourself, or if you are planning to facilitate one on behalf of another person, you must read and absorb these monographs. To our knowledge there is no other set of resources published that gives a reader the information needed to think, to act and to reflect on the excitement and disappointment experienced as circles of support are built, facilitated and maintained over time.

These six monographs take us on a journey through the authors' last five years of learning, discovering and walking with people with disabilities. They use the power of individual stories to illustrate and guide the reader to specific strategies that have supported people to be included in communities.

A wonderful site near the center of West Hartford was chosen for a small, four unit townhouse. In 1989, many forces were converging in West Hartford to support Mary-Ann's dream. However, the neighbors near the site heard about the plan, and at that point, many resistant forces were unleashed.

A series of tense and unpleasant public meetings revealed community members' concern about property

values and general prejudice against people with low incomes. The development of the co-op was seriously threatened by this outbreak of discrimination.



values and general prejudice against people with low incomes. The development of the co-op was seriously threatened by this outbreak of discrimination.

Mary-Ann, her family, her support circle, and the members of the Interfaith Coalition rallied community support. Mary-Ann and her supporters spent several days in West Hartford gathering petitions from those in favor of the Cooperative. Mem-

bers of the Interfaith Coalition organized people from nine churches to testify at a public hearing. The tension of opposing forces gathered as the night of the public hearing grew close.

The events of the public hearing were awesome. First, the meeting was moved from the town hall to a public school auditorium because so many people arrived to present their views. Finally the testimonies by neighbors opposed to the development began. Their fears of people with low incomes were disguised in meaningless

discussions regarding architectural details. Town officials appeared to grow tired and weary as the evening hours passed.

Slowly the powerful testimonies of those in favor of the townhouse began to override the shallow arguments against it. Proponents spoke of justice, decency, equality, and morality. Mary-Ann concluded the testimonies with her moving personal story of her own situation. The applause of her supporters filled the auditorium. In the days that followed, the town council voted in favor of the development. Months later, Mary-Ann applied and was accepted into the cooperative development.

- FROM PERSON-CENTERED DEVELOPMENT

These monographs are filled with stories such as Mary-Ann's. The stories are woven into practical strategies and suggestions to guide us on our own walks through our neighborhoods and communities. The strategies are presented in an easy to read manner, through the use of personal stories, diagrams, poetry, quotes, lists, tables, and narrative information. By using all these different methods of transmitting their information the authors have attempted to touch each of us personally. As we read through each page we learn with the authors and their contributors.

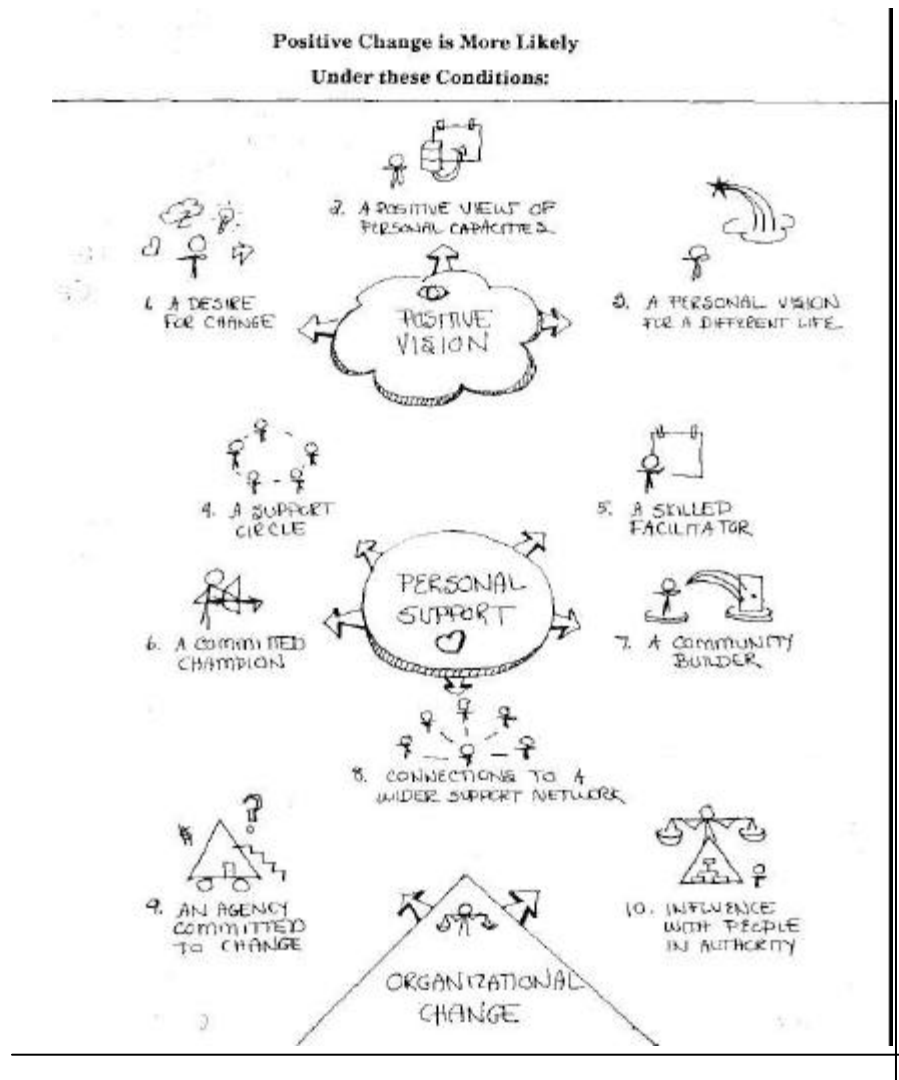
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Person-centered change challenges us to engage with people as friends and allies instead of remaining distant from people in professional roles. The more we encourage people to dream and work for their highest ideals, the more we must learn to live with their struggle.

- FROM IMPERFECT CHANGE

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We are learning that real personal change requires more than a personal futures planning meeting and development of a circle of support. Circles of support can initiate the personal support needed to help people dream and take on the challenges required of the dream. However, circle meetings are like punctuation marks in a story,



rich with action, disappointment, friendship, allies, enemies, barriers, accomplishment, clarity, confusion, strategy, and mystery. Many other activities are needed to sustain the action of a group over time."

- FROM DARE TO DREAM

The advice given in these monographs is powerful. At times I read through them and I say to myself "good point". It seems that what they are saying is so simple and practical, but I never looked at it that way. Sometimes I find myself laughing at a story or at the way a point is made and a couple of pages later I find myself crying at the joy or sadness of a particular situation or story. At other times I yell out, "RIGHT ON!"

If we are going to walk this path with people, we must clear away many of the distractions and practices of system-centered work that distance us from people. We must find ways to restructure frustrating services and redistribute resources to make the journey smoother for people. We must find new ways to build personal relationships that offer encouragement and support in the face of conditions that hurt.

We must find ways to live with the tensions ourselves, to channel the energy of discomfort into construc-

tive action, to turn feelings of helplessness into strategies for change, to turn the downward spiral of depression into an outward call for relationship.

- FROM IMPERFECT CHANGE

?

Without people to encourage, help, and support, the road is very hard indeed for a person working towards a vision and focusing on capacity. If people could do it by themselves they would, but the obstacles are so immense. Because of the history of being seen as deficiencies, people with disabilities often times have given up hope. Circles of support have been a group developed to focus the collected abilities and capacities of a natural group of family, friends and neighbors."

- FROM ONE CANDLE POWER

What these monographs illustrate so clearly to me is that life is a continual struggle filled with many joys and many difficulties. It seems most people are just asking for a chance to experience these struggles. Ed Riley's story taken from "Imperfect Change" illustrates this point:

PLANTING THE SEED
OF UNDERSTANDING, by
Everett Cook, Personal Care

Attendant and Friend.

The circle of support gave Ed a sense of purpose to his life, something that had been lacking since the time he had to give up many of his activist and support groups. This was something that over the years, Ed fought to make legislators understand; that a life without purpose is not a life at all, but merely an existence. Most disabled people long to make contributions to society equal to their able-bodied brothers. However, due to economic reasons, far too many are forced to live their lives between the bed, the wheelchair, and the television and with time come to view themselves as they are treated, as the excess baggage of life, dutifully carried along, but not really needed. All too often, Ed began to see himself this way.

During the last few years, Ed became very tired. The battles to maintain his day-to-day existence began to sap his strength and left him with little energy and lesser encouragement to do much else. For the time he worked with Pat and George and his support circle, he was able to gain back some of his self respect, and I am thankful for that. How unfortunate for us all, that with all the strength he needed to fight to carry on these simple daily activities, he was left with little left over to fight that final battle.

His life and his death stand as a lesson in the importance of planting the seed of understanding in all individuals, both at the personal and legislative levels; and of affecting people's lives, so that all members of society, regardless of disability, may be treated with the respect they deserve and be allowed to demonstrate their value as active members of society.

Ed took great personal risks to live a full life in spite of the institutions and bureaucracies that promised him little. While he inspires many others with his spirit and courage, he lived with high hopes and great despair. The people closest to him shared his vision and were moved to personal and political action while sharing his journey. Ed influenced the implementation of Personal Care support reforms that will make it possible for many other people to move from nursing homes and other institutions to live in their own homes without life-threatening risks.

- FROM IMPERFECT CHANGE

These monographs are a valuable resource which can assist us in building community and in understanding person-centered development. Without a doubt these six monographs present us with some of the most thoughtful, provocative, exciting and valuable information which can be used as a guide to creating

more inclusive communities. Buy the whole series and read them over and over again. Give them as presents to people you care about, set your expectations high, and believe in dreams.

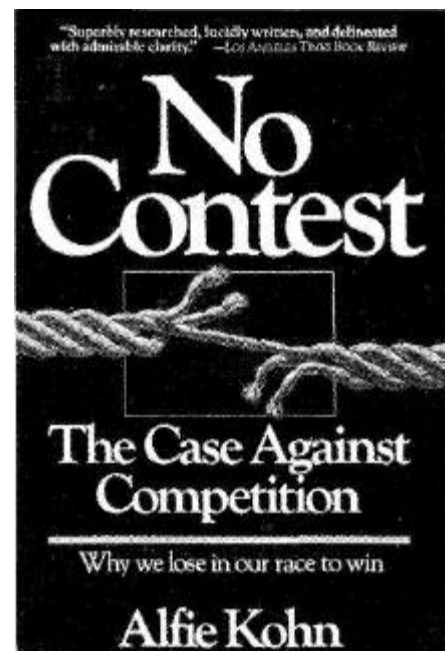
Afterword: Dreams and Expectations

Four years ago I could not have imagined how my life is today. My expectations were limited, and I thought of our dreams as impractical, unrealistic visions of a future that could never be. Whenever a dream did surface, I tended to ignore it so I wouldn't get too attached to it. No wonder so few dreams became reality during this time!

But during these three-and-a-half years, while I have dared to dream (and sometimes dreamed extravagantly), my expectations have quietly increased. My perception of what is possible has grown. Things I once thought as absolutely out of the question have already been accomplished, so new opportunities are welcomed with anticipation and joy. New endeavors may look like a minor challenge or a significant stretch, but I do not automatically reject any of them. I can now understand the length of the journey I am on, and realize that this is only the beginning.

— FROM DARE TO DREAM

No Contest: Why We Lose in Our Race to Win



No Contest: The Case Against Competition - Why We Lose in Our Race to Win, Alfie Kohn; 1986; 257 pp.; \$8.95 from : Houghton Mifflin Company, 2 Park Street, Boston, Mass. 02108

Boris had trouble reducing "12/16" to the lowest terms... Much heaving up and down and waving of hands by the other children, all frantic to correct him.... She then turns to the class and says, "Well, who can tell Boris what the number is?" A forest of hands appears, and the teacher calls Peggy

[who successfully answers the question]. Thus Boris' failure has made it possible for Peggy to succeed; his depression is the price of her exhilaration; his misery the occasion for her rejoicing. This is the standard condition of the American elementary School.... To a Zuni, Hopi, or Dakota Indian, Peggy's performance would seem cruel beyond belief.

Something far more significant and lasting than fractions is being taught here. Boris will likely grow up despising the Peggys he encounters, perhaps fanning that wrath until it takes in all women or some other group that seems to include too many winners. Perhaps he will be unequal to the demands of active rage and will simply slink through life a confirmed failure. In any case, he and Peggy will take from this classroom a common lesson: other people are not partners but opponents, not potential friends but rivals.

In a hypercompetitive society, it is never too early to begin such training. Most recently, "readiness programs" have appeared to prepare infants for "the feverish competition at the better nursery schools." By the time of elementary school, the pressure to be number one is nothing new, but it has just begun to be codified and quantified.

Community as we envision it is a place of cooperation, a place of mutual regard - mutual respect, a place where there is no "top of the heap", a place where individual gifts are discovered and nurtured - a strange place indeed as we experience life in our neighborhoods and cities today. Too often we experience the opposite — competition in its most negative form.

Alfie Kohn has written a book that challenges all of us who have grown up in 20th-century America. He suggests that we rethink the whole notion of competition. When we seek to include people with very significant differences into the fabric of our community life, we must concentrate on cooperative ways of doing things, since competition in the traditional sense of the term is not possible. In fact it may be that one of the great gifts of people with significant disabilities is to allow us to learn this lesson.

No Contest is the first book to argue that competition is inherently destructive. In the classroom and the family, in athletic contests and business rivalries, we are encouraged to pit ourselves against one another and taught that competition is a prod to productivity, a builder of character, and an unavoidable part of "human nature." In this well-researched and carefully reasoned study, Alfie Kohn

systematically refutes these myths. He demonstrates that gaining success by making others fail is an unproductive way to work or learn, a behavior devastating to individuals and society. Any win/lose structure is psychologically destructive and poisonous to our relationships, so that "healthy competition" is a contradiction in terms.

/ was out of school for twenty years before I began to understand the destructive power of this competitive approach to education: in every classroom, twenty or thirty children receive the hidden curriculum of competition, every school day, for twelve or more years. Is it any wonder, then, that we are so disabled in our capacity to cooperate - in marriages, work settings, neighborhoods, churches, friendships ?

The movement towards full participation and inclusion of people with disabilities not only requires, but causes, us to come to grips with competitiveness per se. We have seen entire schools converted to cooperative educational models because they made a commitment to the full inclusion of children with disabilities, and were faced with the fact that competitive education simply didn 't work. It raises the possibility that our current frenzy to "compete with the Japanese" could do with another look.

-DW

Learning to Think Regeneratively

BY ROBERT ROD ALE	Internal	External
<p>Find a way to make the pie you have bigger, rather than looking for someone willing to give you a new pie.</p> <p>That's the basic idea of regeneration.</p> <p>Sounds good on its face. But how do you actually do it? How do you begin thinking in ways that let you see the potential in any "pie-expanding" project that may interest you?</p> <p>The first step is to learn how to think systematically about capacity, rather than needs. Most people are needs-oriented in their thinking. They make lists of wishes and wants. And when they start working on what should be a regenerative project — like improving the economy of a neighborhood or town — they begin by making a needs inventory. "If we only had more of this or that," they believe, "we would begin to make some progress around here."</p> <p>Sure, you are going to need some things from outside to get a project moving. But to tap into regenerative potential, understanding capacity must come first. A clear view of the capacity of a system to regenerate will define its needs more accurately.</p>	<p>SOIL</p> <p>SUN - main source of energy</p> <p>RAIN - main moisture source</p> <p>NITROGEN - collected from air and recycled</p> <p>MINERALS - released from soil reserves and recycled</p> <p>WEED & PEST CONTROL - biological and mechanical</p> <p>ENERGY - some generated and collected on farm</p> <p>SEED - some produced on farm</p> <p>MANAGEMENT DECISIONS - by farmer and community</p> <p>ANIMALS - produced synergistically on farm</p> <p>CROPPING SYSTEM - rotations and diversity enhance value of all components above</p> <p>VARIETIES OF PLANTS - thrive with lower moisture and fertility</p>	<p>HYDROPONIC MEDIUM</p> <p>SUN - energy used as 'catalyst' for conservation of fossil energy</p> <p>IRRIGATION - main moisture source</p> <p>NITROGEN - primarily from synthetic fertilizer</p> <p>MINERALS - mined, processed, and imported</p> <p>WEED & PEST CONTROL - with pesticides</p> <p>ENERGY - dependence of fossil fuel</p> <p>SEED - all purchased</p> <p>MANAGEMENT DECISIONS - some provided by suppliers of inputs</p> <p>ANIMALS - feed lot production at separate locations</p> <p>CROPPING SYSTEM - monocropping</p> <p>VARIETIES OF PLANTS - need high level inputs to thrive</p>

And there's something even more important. New inputs into a system can diminish its capacity to regenerate. That must be guarded against. After making the decision to become a capacity-oriented thinker, step two is to list specific internal resources which make up the capacity of the people and the environment to be regenerated. What are internal resources? They are the abundant, available, paid-for things that can be used for the production of new ideas. Every useful thing other than an input is an internal resource. They are the raw materials for regeneration. Internal resources are also what you want to regenerate.

At this point, a specific example might be helpful. Above, you will find a diagram headed Resource Systems for Agricultural Production. The column on the left lists the internal resources of a typical farm. And on the right are listed the external inputs often used for farming.

Please take some time now and look at the chart. Note that twelve separate categories of resources are listed in each column, and that they are paired. A farmer can choose to get each of the resources from either the left column or the right - from internal resources or from external inputs. Or, he can use a combination of the two. It is also important to realize that in the case of

farming, internal resources are all that's needed to produce at least some food and fiber. Agriculture is about 10,000 years old, than for 9,900 years, all farmers the world-over used only internal resources. There were no farm inputs until a century ago.

What happened in those hundred years? Yields of farm crops have gone way up. A vast, world-wide agribusiness has been established. But there has been a dark side too. Erosion of soil and pollution of the farm environment have increased dramatically. Millions of people who wanted to live as farmers have been forced off the land by low commodity prices and bad conditions in general. It is clear that the remarkable productivity of agriculture during the last century has been matched by profound degeneration as well.

A discussion of the internal resources diagram can show why that degeneration happened. In many cases, the introduction of external inputs into agriculture unnecessarily diminished the vitality and usefulness of the internal resources. Many of the inputs listed on the right side of the chart "invaded" the territory of the internal resources listed on the left.

The primary objective of a regenerative agriculture is not to eliminate the use of inputs - although some regenerative farmers may succeed in doing

that. The purpose of regeneration in agriculture is to expand the functional capacity and vitality of the internal resources.

Regenerative strategies in agriculture can push the line in separating internal resources from external inputs - although some regenerative farmers may succeed in doing that. The purpose of regeneration in agriculture is to expand the functional capacity and vitality of the internal resources.

Regenerative strategies in agriculture can push the line separating internal resources from external inputs from the middle of the sheet to the far right side. That can be done in two ways. One is to think about each of the twelve resource categories separately and create tactics to reduce the need for each of the specific inputs. The second way is to plan synergistic interactions that make the better use of all the internal resources.

For example, more nitrogen can be collected "internally" on farms by making better use of all the individual internal resources. In fact, each resource is inextricably related to all the others, and every one has to be brought into a regenerative plan.

Of course the goal of that plan is not only to get more production out of the farm system, but to regenerate it as well. So if a farmer can expand the left side of the resource diagram representing that

particular farm, fewer inputs will be needed and the resource base of that farm will be regenerated as well. And so will the human community which makes that farm its home.

The resource diagram therefore becomes the framework for thinking about regeneration. And if a similar resource diagram can be made for each of the categories on the master diagram, a much more focused plan for regeneration will be created.

Make Your Own Resource Diagram

Now that you have at least a general idea of the process, you can begin making a regenerative resource diagram of your own. Start by deciding where you want to try to apply the regenerative process. Perhaps you are interested mainly in community regeneration. If so, you could diagram the resources and inputs of a typical town. Or you could make one for your specific town, city or neighborhood.

Another idea is to make a resource diagram of yourself - as a way to begin a program of personal regeneration. Some people may even want to make regenerative resource diagrams for their gardens. And there is no reason why a regenerative resource diagram couldn't be made for a business, or a department in a company.

That would lead the way to the creation of regenerative approaches to management.

Be prepared for some hard work though. A regenerative resource diagram may look like nothing more than a collection of a few words and lines on one sheet of paper. But in reality it represents the end product of a considerable amount of thinking. And regenerative thinking is particularly difficult because there is not a broad body of regenerative literature and prior to thinking to draw inspiration from. True, we can find some benchmarks and signposts to use as guides. But often we will have to decide for ourselves what they are, and where they are located. And in some cases we will have to measure and describe them ourselves.

So I suggest that after you write the title of your regenerative resource diagram across a sheet of paper, and put the words "internal" on the left side and "external" on the right side, you file it for a while and just think. At first, think simply about what the resources are that are needed to accomplish your task or goal. Make notes on separate sheets of paper before starting to work on the diagram itself. Only after you are fairly sure you have listed the most important resources, should you begin to think about how to express them as either internal or external. I hesitate to predict

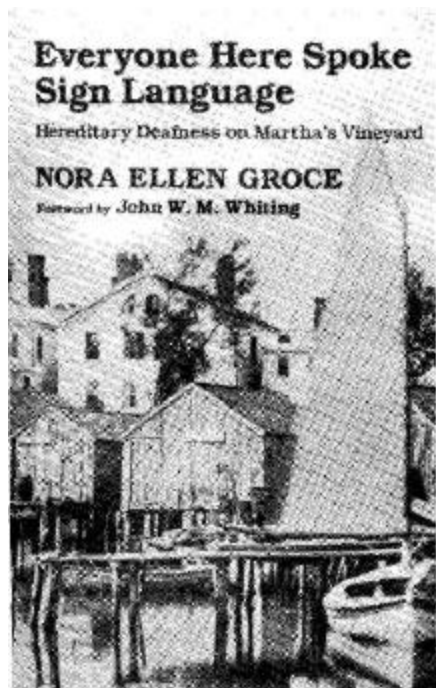
how long it could take you to get through the first stage of thinking and begin actually making your diagram. Much probably depends on whether you've done similar kinds of thinking before, the essential elements of which can be adapted to the regenerative resource diagram format.

Another extremely useful aid should be access to other people. This kind of thinking may be difficult to do alone. One mind, no matter how broad and open to new concepts, may not even have an understanding of all the resources important to a given system. Discussion and brainstorming can therefore speed up the process of making a diagram, and will almost certainly improve its quality.

You can make a regenerative resources diagram alone, though, if you have a clear understanding of regenerative principles. There is much more to regeneration than just a new set of words. Underlying the language of regeneration are very real biological social and economic forces. You need to know enough about them to be convinced that they exist, and can be identified, measured, classified and used.

- FROM *REGENERATION*,
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Everyone Here Spoke Sign Language



Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard, Nora Ellen Groce; 1985; 169 pp.; \$17.95 from: Harvard University Press, Cambridge, Massachusetts

Nora Ellen Groce, an American ethnologist, has discovered a time and place where the handicaps usually associated with a disability (in this case profound hereditary deafness) literally disappeared — or more accurately, never appeared in the first place — because the community had completely adapted to the condition of deafness.

"When is deafness neither handicap nor stigma? When, as this remarkable book recounts, the entire hearing community learns from childhood to be bilingual in conversational speech and sign language, and when the deaf are wholly integrated into the community's social, economic, religious, and recreational life... A vivid ethnography of a hearing community's full acceptance of, and adaptation to, deafness."

- CHOICE

On the mainland profound deafness is regarded as a true handicap, but I suggest that a handicap is defined by the community in which it appears. Although we can categorize deaf Vineyarders as disabled, they

certainly were not considered to be handicapped. They participated freely in all aspects of life in this Yankee community. They grew up, married, raised their families, and earned their livings in just the same manner as did their hearing relatives, friends, and neighbors. As one older man on the Island remarked, "I didn't think about the deaf any more than you'd think about somebody with a different voice."

Perhaps the best description of the status of deaf individuals on the Vineyard was given to me by an Island woman in her eighties, when I asked about those who were handicapped by deafness when she was a girl. "Oh," she said emphatically, "those people weren't handicapped. They were just deaf."

On the Vineyard... the hearing people were bilingual in English and in the Island Sign Language. This adaptation had more than linguistic significance, for it eliminated the wall that separates most deaf people from the rest of society. How well can deaf people integrate themselves into the community if no communication barriers exist and if everyone is familiar and comfortable with deafness? The evidence from the Island indicates that they are extremely successful at this.

"It was taken pretty much for granted. It was as if somebody had brown eyes and somebody else had blue. Well, not quite so much -- but as if, ah, somebody was lame and somebody had trouble with his wrist...."

The community's attitude can be judged also from the fact that until I asked a direct question on the subject, most of my informants had never even considered anything unusual about the manner in which their deaf townsmen were integrated into the society. They were truly puzzled by an outsider's interest in the subject. Almost all informants believed that every small town in New England probably had a similar number of deaf people and adapted to them in much the same way.

I asked this man if he knew about any mentally retarded individuals on the Island, since [Alexander Graham] Bell, in passing, had mentioned several. Well, he said, getting quite serious, he did recall a few, and he proceeded to give me a list of eight names, none of which I had ever heard mentioned as "feeble-minded," to use the local term. Only after checking with several other people did I find out that he had

given me the names of every Democrat who used to live on Martha's Vineyard.

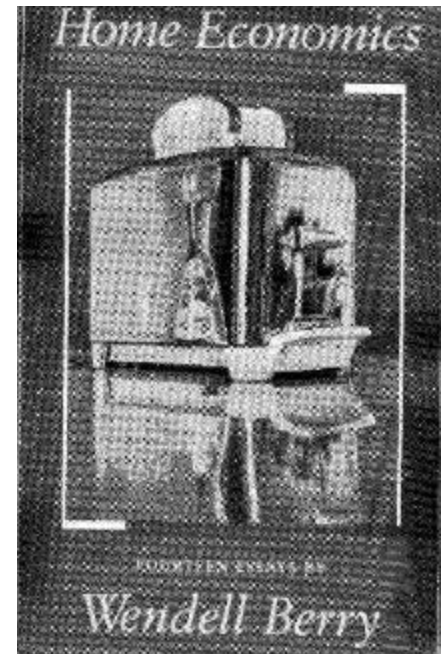
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The most striking fact about these deaf men and women is that they were not handicapped, because no one perceived their deafness as a handicap. As one woman said to me, "You know, we didn't think anything special about them. They were just like anyone else. When you think about it, the Island was an awfully nice place to live." Indeed it was.

The irony about this story is that what seems to have finally broken the connection was the advent of special education at the American Asylum for the Deaf and Dumb, opened at Hartford, Connecticut, in 1817. Deaf children from the Island began to spend the school year off-island; some married partners they met on the mainland, and remained there. Vineyarders with deafness in their families found themselves the subjects of "scientific" inquiry by summer people. For the first time Vineyard deaf people had to contend with some of the problems faced by their off-Island counterparts.

Groce's book is articulate, well-researched, accessible and enjoyable. It reminds us that what we need to make our communities inclusive is at hand.

HOME ECONOMICS



Home Economics: Fourteen Essays, Wendell Berry 1987; 191 pp.; \$9.95 from: North Point Press, 850 Talbot Avenue, Berkeley, CA 94706

Wendell Berry is a Kentucky farmer, writer and teacher of extraordinary insight and power. Although he rarely directly addresses the issue of 'disability', his reflections on regenerating community apply perfectly to our task of recovering the vitality our own extended families, neighborhoods, churches and friendships. We have shared Wendell Berry's writing with people who work in other fields, and found that his books have the power to create a "bridge" of understanding and common interest. We discover

who would still be in place had they been willing for their neighbors to survive along with themselves. In light of this, we see that the machines, chemicals, and credit that farmers have been persuaded to use as "labor savers" have, in fact, performed as neighbor replacers. And whereas neighborhood tends to work as a service free to its members, the machines, chemicals, and credit have come at a cost set by people who were not neighbors.

What I am proposing, in short, is that farmers find their way out of the gyp joint known as the industrial economy. The first item on the agenda, I suggest, is the remaking of the rural neighborhoods and communities. The decay or loss of these has demonstrated their value; we find, as we try to get along without them, that they are worth something to us - spiritually, socially, and economically. And we hear again the voices out of our cultural tradition telling us that to have community, people don't need a "community center" or "recreational facilities" or any of the rest of the paraphernalia of "community improvement" that is always for sale. Instead, they need to love each other, trust each other, and help each other. That is hard. All of us

know that no community is going to do these things easily or perfectly, and yet we know that there is more hope in that difficulty and imperfection than in all the neat instructions for getting big and getting rich that have come out of the universities and the agribusiness corporations in the past fifty years.

We must be aware too, of the certainty that the present way of things will eventually fail. If it fails quickly, by any of several predicted causes, then we will have no need, being absent, to worry about what to do next. If it fails slowly, and if we have been careful to preserve the most necessary and valuable things, then it may fail into a restoration of our community life — that is, into understanding of our need to help and comfort each other.

*- Wendell Berry,
The Hidden
Wound*

The Merry-Go-Round Man

KATHY LEE & DEB OSTROFSKY

Have you ever felt that life is one big lesson? Ever wonder what you could have done (or neglected) to be sentenced to eighty years or so of continuing education?

I found myself at Conneaut Lake Park with Connie and Peg one hot summer day not long ago. I remember feeling a little like the "Quantum Leaper" - vaguely removed from time and place - wondering why I was there and just what it was I was there to do. I leaned on Peg's chair thinking "poor me" thoughts as I pushed her along. My roommate, Connie, followed slowly. It was sooooo hot, and we had walked all day. It was disability day at the park, which I think is sort of queer, but Peg and Connie had wanted to come. It was free, so there we were. Now, I've known Peg for years and most of the time I really enjoy her company, but like I said, it was sooooo hot, I was tired, and yes, I felt stuck.

Connie wanted to ride the Merry-Go-Round so we

ambled off in that direction. Lots of adults were riding the Merry-Go-Round, so I decided it wasn't too weird for Connie to want to ride. Peg and I waited in line with her. Several minutes and three feet later, the Merry-Go-Round man pointed at Peg and said, "Bring her around to the back gate." I opened my mouth to say something like, "That's okay, we're just waiting with Connie," then looked at Peg and shut my mouth. Peg was so excited! She had complained earlier that all she had ridden was the train. I thought it was amazing that she had ridden anything - her wheelchair is really heavy and she can't help too much when she's being moved without it. I remember wishing that she could be grateful she had ridden *something* while she complained and looked disappointed.

Okay, I thought, looking at the Merry-Go-Round man, I'll bring her around to the back gate, but you'll see. I've helped lift this woman for years, and there is no way that you and I are going to get her on the Merry-Go-Round.

We reached the back gate, the Merry-Go-Round man opened it and motioned up. "Okay", he said. "Let's lift her." Right, I thought. The guy wasn't all that big or strong looking, and the Merry-Go-Round was at least

a foot off the ground.

"Are you sure? I think she's too heavy for us", I said. I felt terrible the minute the words left my mouth, knowing how much Peg wanted to ride, but there was just no way around it.

"No, let's lift her up", said the Merry-Go-Round man. Okay, I thought, looking at the gap between the ground and the Merry-Go-Round, let's show him. We'll give it a try, he'll find out we can't do it, and at least Peg won't be mad at me. She'll see that she's really too heavy.

The Merry-Go-Round man said "Lift at the count of three" and grabbed the side of Peg's chair closest to him. He even had the wrong grip - the worst way you could lift anyone in a chair - and like I said, he was a little guy. Well, one two, three, and we lifted her up.

The Merry-Go-Round went around, Peg was beaming, and I stood frozen like a cigar store Indian. I can't believe we're on this Merry-Go-Round, I thought. Twice we rode while I thought, "I can't believe..." and Peg smiled.

The ride stopped, it was time to get off, and on the count of three Peg got off the Merry-Go-Round. "Have a nice day", said the man. Have a nice day? Have a nice day? Buddy, you MADE her day.

for me. She in turn, is limited by being known well only by me and by my limited thinking about what was possible for her - and that's not good for her.

I like the part of me that cares for others, dreams for others, and gives of what I have so others can have more. I'm growing less fond of the part of me that depends on what I get from that - the responsibility and the credit. My belief that certain things should happen for Peg, and my determination that I (wonderful I) would be responsible to make them happen was sure taking lots of the fun out of helping. Many exciting things have happened for Peg - like she has recently moved into town from a nursing home. Much of that process was really fun, although not so much fun when she was frustrated, disillusioned or not grateful enough to my way of thinking. I hate it when I think she doesn't appreciate the things I do for her.

I realize I was facilitating, conceptualizing and preparing for things I needed to let others do or just let happen. Analyzing instead of enjoying. My special training and intimate knowledge and love of Peg had become such a lonely, ought to, only-I-can-so-I-have-to sort of thing.

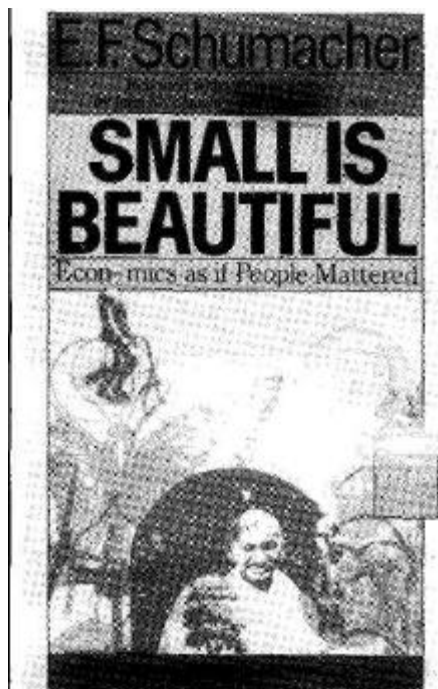
I don't know who sent the little man at the Merry-

Go-Round to Peg and I, but the absolute value of community, of people helping people, is a little clearer for my experience at the park. "Community" is *the* word talked by people I respect in my field, and I am gaining a better appreciation of why this is so. The little man at the Merry-Go-Round, just doing his job of getting people on the ride - without "wheelchair lifting training" - lifted us both up, broadened our perspectives and gave us both hope. Peg and I are both lighter these days. Maybe that guy wasn't so little after all....

So the public realm where strangers meet is finally a proving ground of faith. In every encounter with every stranger we are given the chance to meet the living God. No matter how often we turn that chance down, it is offered again and again and again.

*- Parker Palmer
The Company of Strangers, p. 67*

Small is Beautiful



Small is Beautiful,
E.F. Schumacher; 1989; 324
pp.; \$9.95 from: Harper &
Row, 10 East 53rd Street,
New York, NY 10022

This book has had a profound influence on our work. George read the book nearly 20 years ago and was deeply moved at the time, but didn't know how to put it into practice in the field of disability. However, the book has taken on more and more meaning as we have moved from a focus on disability to a focus on community inclusion, and as we listened to the words of John McKnight and read the words of third world authors.

This work deserves permanent space in the libraries and read-

ing lists of those of us interested in community, particularly communities that enhance and encourage people in ways that are available to all societies, not just societies highly sophisticated and highly technologically inclined. E.F. Schumacher, in his original work, and the organizations that have developed because of his work, bring ways of feeding, housing and enhancing the lives of everyone, particularly those who live in Third World countries.

For us in the field of disability, it seems the more complicated we try to get within our service delivery systems, the more we make technological issues more important than simple human caring for one another — people gathering to support one another in very simple ways. For those who are interested in the idea of full participation and inclusion, this book and what it teaches us is very important.

Just as Democracy in America set us all in motion regarding the importance and value of community associations, so too, Small is Beautiful has us focusing on what each of us can do in simple straightforward ways.

—PAT BEEMAN

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Scientific or 'technological' solutions which poison the environment or degrade the social structure and man himself are of no benefit, no

matter how brilliantly conceived or how great their superficial attraction. Ever-bigger machines, entailing ever-bigger concentrations of economic power and exerting ever-greater violence against the environment, do not represent progress: they are a denial of wisdom. Wisdom demands a new orientation of science and technology towards the organic, the gentle, the non-violent, the elegant and beautiful. Peace, as has often been said, is indivisible — how then could peace be built on a foundation of reckless science and violent technology? We must look for a revolution in technology to give us inventions and machines which reverse the destructive trends now threatening us all.

What is it that we really require from the scientists and technologists? I should answer: We need methods and equipment which are: cheap enough so that they are accessible to virtually everyone; suitable for small-scale application; and compatible with man's need for creativity.

What is quite clear is that a way of life that bases itself on materialism, i.e., on permanent, limitless expansionism in a finite environment, cannot last long, and that its life expectation is the shorter the more successfully it pursues its expansionist objectives.

3.

Re- Visioning Ourselves

Those who live with a radically different vision of people who have disabilities often means coming into contradiction with the values and dynamics of the prevailing culture. We discover the work involves a deep and continuous "letting go" -- of security, of approval, of life in the fast lane. As my friend Alan Etmanski says, it requires a *descending* — which is difficult indeed in a culture that is obsessed with ascendancy and power. John McKnight speaks about "unreasonable commitments"; Vanier of "the broken body"; and Christopher Alexander of the requirement to overcome deeply-rooted fears. All of this is difficult work. There is a gift (that comes unsought), but what are our sources of personal sustenance, hope, and affirmation?

This section of the Catalog is devoted to that part of us that *is*, rather than does; it draws upon the sources which have inspired and sustained our friends. Wendell Berry begins...

The Zen student, the poet, the husband, the wife - none knows with certainty what he or she is staying for, but all know the likelihood they will be staying "a while:" to find out what they are staying for. And it is the faith of all these disciplines that they will not stay to find out that they should not have stayed. That faith has nothing to do with what is usually called optimism. As the traditional marriage ceremony insists, not everything that we stay to find out will make us happy. The faith, rather, is that by staying, and only by staying, we will learn something of the truth, that the truth is good to know, and that it is always both different and larger than we thought. We must accept the duration and effort, even the struggle, of formal commitment. We must come prepared to stay.

- Wendell Berry, *Standing by Words*, p. 206

This is probably a good place to make it clear that our focus on community and on the freely-given commitments of family and friends does not mean that we are anti-professional or that we think that people who have found their vocations in human service ought to be shunned. We have seen far too many acts of love, and courage, and sustained devotion to believe that professional training or employment in a service agency strips one of membership in the human community. Many professionals struggle against the limits imposed by systems, and are good stewards of the resources which have been committed to their care. And professional identity does not take away one's identity as a citizen. Each of us, while we may be required to *do* for many, can *be* the friend, or parent, or bridge-builder that one person needs.

How Can I Help?: Stories and Reflections on Service



"Fear is the mind's reaction against the inherent generosity of the heart. Because the heart knows no bounds to its giving, the mind feels called upon to define limits."

How Can I Help?: Stories and Reflections on Service, Ram Dass & Paul Gorman; 1988; 243 pp.; \$6.95 from: Alfred A. Knopf, Inc., New York, NY

When we embark on a path of service (and we all do, in our ordinary roles as parents, friends, professionals, and citizens), we may discover that we are on a journey of spiritual-psychological-emotional "straightening." Sooner or later, the path of service raises all of the ego-demons, as well as the fear, resistance and selfishness with which we are encumbered. Ram Dass and Paul Gorman know the path, and have gathered stories and reflections that are of practical, delightful use to the parent, spouse, friend and helper in each of us.

George Durner once told me that his main work as director of a L'Arche community was to give the people who worked there regular opportunities to reflect on what they were experiencing. How Can I Help provides a multi-faceted mirror to help with that reflection.

Over Gandhi's tomb are inscribed words that say: Think of the poorest person you have ever seen and ask if your next act will be of any use to him. That'll flash through my mind as I prepare to throw a Frisbee. And

when I spend fifteen bucks dining out and going to a movie to ward off boredom, I might recall that a fifteen-dollar operation could restore someone's sight in a third world country. I'm moved by the power of Gandhi's invitation, "Live simply that others might simply live." But I'm not at all clear about how to heed that, day in and day out, here in the affluent West. Sometimes I feel a little guilty.

One day a rabbi, in a frenzy of religious passion, rushed in before the ark, fell to his knees, and started beating his breast, crying, "I'm nobody! I'm nobody!"

The cantor of the synagogue, impressed by this example of spiritual humility, joined the rabbi on his knees. "I'm nobody! I'm nobody!"

The "shamus" (custodian), watching from the corner, couldn't restrain himself, either. He joined the other two on his knees, calling out, "I'm nobody! I'm nobody!"

At which point, the rabbi, nudging the cantor with his elbow, pointed at the custodian and said, "Look who thinks he's nobody!"

The suffering of others spontaneously releases our desire to help out. Our heart

begins to open. But then there's a thought: Is this problem too heavy? Do I have what it takes? If I offer to help, will I ever get away? Set off by fear, the mind is startled into self-defense. The fear, of course, is in part a reaction to the suffering itself. But also a response of resistance to the heart's natural compassion as it reaches out to engage someone's pain.

Fear is the mind's reaction against the inherent generosity of the heart. Because the heart knows no bounds to its giving, the mind feels called upon to define limits. Under such tension, little wonder our choices of how to respond to the pain of others seem so difficult.

The more deeply we listen, the more we attune ourselves to the roots of suffering and the means to help alleviate it. It is through listening that wisdom, skill, and opportunity find form in an act that truly helps. But more than all these, the very act of listening can dissolve distance between us and others as well.

Heard...If they only understood how important it is that we be heard! I can take being in a nursing home. It's really all right, with a positive attitude.

My daughter has her hands full, three kids and a job. She visits regularly. I understand.

But most people here... they just want to tell their story. That's what they have to give, don't you see? And it's a precious thing to them. It's their life they want to give. You 'd think people would understand what it means to us... to give our lives in a story.

So we listen to each other. Most of what goes on here is people listening to each other's stories. People who work here consider that to be... filling time. If they only knew. If they'd just take a minute to listen!

This is the vision spiritual traditions offer: service as a journey of awakening. The value of such a perspective on our work is not so much that it leads to exalted states and indescribable experiences. It is enough that it can help keep us straight.

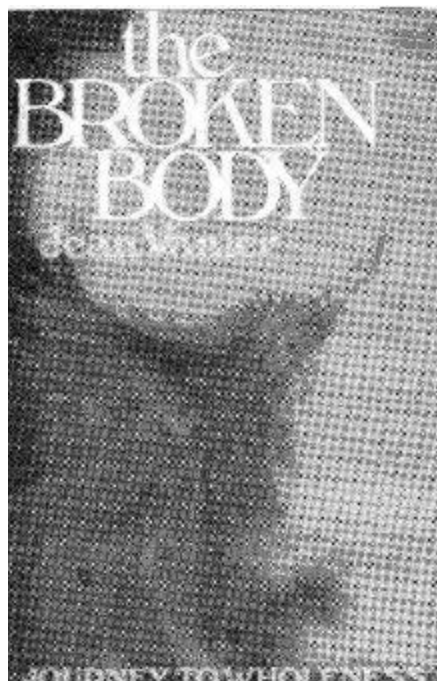
What is it that so touches us about a single caring act or a life surrendered into service? Perhaps we see our deepest yearnings reflected in others, and this encourages us to believe in our own purity and beauty. These are no longer just ideals to strive for. We can reach them, we can be that way. Images of compassion beckon and encourage us onward.

But finally their fantasies paled before the fact, which was simply that they kept going out on the road, year after year, and played harder, longer, and straighter for the people than anyone else.

*- Nik Cohn,
A History of Rock
and Roll, on The Who*

To use knowledge and tools in a particular place with good long-term results is not heroic. It is not a grand action visible for a long distance or a long time. It is a small action, but more complex and difficult, more skillful and responsible, more whole and enduring, than most grand actions. It comes of a willingness to devote oneself to work that perhaps only the eye of Heaven will see in its full intricacy and excellence. Perhaps the real work, like real prayer and real charity, must be done in secret.

*-Wendell Berry,
The Gift of Good Land,
p. 281*



The Broken Body: Journey to Wholeness

The Broken Body, Jean Vanier; 1988; 145 pp.; \$8.50 from: Paulist Press, 997 MacArthur Boulevard, Mahwah, New Jersey 07430

Coming from a strong Christian base, Jean Vanier shares a vision of wholeness that can help us live with our the pain that is an unavoidable element of walking with people with disabilities. He challenges us to come to a deeper understanding of our own weakness in order to accept the weakness of others in our lives — people who hurt us, people with disabilities, people who are old and frail.

Vanier's theological and philosophical view is one which has enriched the lives of millions throughout the world. He speaks most eloquently about a vision of a completely inclusive community where the gifts of each are equally valued. This vision of inclusion, cooperation, acceptance and forgiveness is one which all of us, regardless of our theological and philosophical view, can find inspiring and enlightening.

- GEORGE DUCHARME

He who attempts to act or do things for others or for the world without deepening his own self-understanding, freedom, integrity, and capacity to love, will not have anything to give others. He will communicate to them nothing but the contagion of his own obsessions, his aggressiveness, his ego-centered ambitions, his delusions about ends and means, his prejudices and ideas.

- Thomas Merton

To love is to open our hearts to people,
to listen to them,
to appreciate them
and see in them their own unique value,
to wish deeply that they may live and grow. To
love is to give our lives for one another. It is to
forgive,
and be compassionate, p. 37

Each of us is called to experience both ecstasy and pain,
shunning neither one nor the other,
but entering into that mystery
where one leads to the other,
where misery and mercy embrace
and wholeness rises from brokenness. p. 62

Do not be surprised at rejection by broken people.
They have suffered a great deal

at the hands
of the knowledgeable and the powerful -
doctors, psychologists, sociologists, social workers,
politicians, the police and others. They have
suffered so much from broken promises, from people
wanting to learn from experiments or to write a thesis
and then, having gained what they wanted -votes,
recognition, an impressive book or article -going away
and never coming back.

Through a caring, committed presence,
people will discover
that they are allowed to be themselves;
that they are loved and so are lovable;
that they have gifts
and their lives have meaning;
that they can grow and do beautiful things
and in turn be peace-makers in a world of conflict.

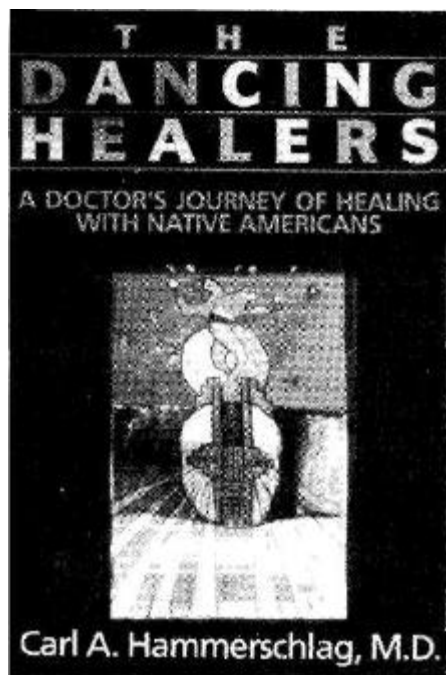
It is true that some people are called to govern
and do things on a larger scale,
to make laws that are just.
Some are called to create jobs;
others must work in healing and in social professions;
still others teach.
All are necessary.
A society composed of many people,
with many roles.
But in all these roles
the same principle applies:
small is beautiful.
We must create situations and communities
where each person
- especially the poorest and the weakest -
can attain human dignity,
find fulfilling work and the warmth of family life
and rejoice in the good news of Jesus.

This is the vocation of us all: to live real and loving
relationships, to be peace-makers, creating and
recreating the body of community.

*IN A SOCIETY THAT
PRESENTS INDEPEN-
DENCE AND SELF-
RELIANCE AS IDEALS,
GRATITUDE IS TAKEN AS
A SIGN OF WEAKNESS.
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VISION, FROM SEEING
THE LOAVES AND FISHES
AS SCARCE PRODUCTS
TO BE HOARDED, TO
SEEING THEM AS
PRECIOUS GIFTS FROM
GOD WHICH ASK TO
GRATEFULLY BE
SHARED, IS THE
MOVEMENT FROM
WREAKING DEATH TO
BRINGING FORTH LIFE,
THE MOVEMENT FROM
FEAR TO LOVE.*

*- HENRI NOUWEN,
LIFESIGNS, PP. 68-69*

The Dancing Healers



The Dancing Healers: A Doctor's Journey of Healing with Native Americans, Carl A Hammerschlag, M.D.; 1989; 170 pp.; \$8.95 from: Harper and Row, Publishers, San Francisco

This book comes to life through the author's stories describing his twenty years in the Indian Country of the Southwest, United States. One such story called Santiago's Dance illustrates how the book breathes life.

"I was beginning to be ready to learn that the spirit plays as big a role in our wellness and sickness as the mind and the body do. I was, by now, becoming quite ripe for Santiago Rossetta.

Santiago, also from Santa Domingo, had been admitted to the Santa Fe Indian Hospital with congestive heart failure. I didn't know he was a Pueblo priest and clan chief. I only saw an old man in his seventies lying in a hospital bed with oxygen tubes in his nostrils.

Suddenly there was a beautiful smile, and he asked me, "Where did you learn to heal?"

Although I assumed my academic credentials would mean little to the old man, I responded almost by rote, rattling off my medical education, internship, and certification.

Again the beautiful smile and another question: "Do you know how to dance?"

Somehow touched by whimsy at the old man's query, I answered that, sure, I liked to dance; and I shuffled a little at his bedside. Santiago chuckled, got out of bed, and short of breath, began to show me his dance.

"And will you teach me your steps?" I asked, indulging the aging priest.

Santiago nodded. "Yes, I can teach you my steps, but you will have to hear your own music."

When I came to Indian country as a young doctor, I thought I was bringing truth, healing and knowledge to a

backward people.... I am a better healer now.... Patients are the principal agents in their lives, and as much as they want to be well, they want peace and understanding. To find such a healing peace they need to feel that a connection exists between themselves and the healer and between themselves and something larger than self or science....

We are always patients, and sometimes we are healers. We move from being one to being the other. Sometimes I do the work, and sometimes someone else does the work.

Here are some of my own stories. I hope my mentors will smile at my dance. They have taught me the steps.

Through these wonderful stories of Native American communities Hammerschlag challenges us to look at the connectedness of all people. Again, in the authors words, "When we see this universal connection among all who have walked the earth, it becomes clear that all history is the history of our time. All stories speak to each of us. Understanding this connection is crucial if we're to be able to live together and to live with ourselves."

After reading this book the reader wants to experience these connections immediately.

- JAY KLEIN

ON COMMITMENT

*Until one is committed,
there is hesitancy, the
chance to draw back..
Always ineffectiveness.*

*Concerning all acts of initiative and
creation there is one elementary
truth, the ignorance of which kills
countless ideas and splendid plans:
that the moment one definitely
commits oneself, then providence
moves too.*

*All sorts of things occur that
would never otherwise have
occurred.*

*A whole stream of events
issues from the decision,
raising in one's favor
all manner of unforeseen incidents
and meetings and material assistance
which no one would have dreamt
would come his way.*

*I have learned a deep respect for
one of Goethe's couplets —*

*"Whatever you can do or dream
you can, begin it.*

*Boldness has genius,
power, and magic in it."*

— W.H. Murray

*I come, in conclusion,
to the difference
between "projecting"
the future, and mak-
ing a promise. The
projecting of "futu-
rologists" uses the
future as the safest
possible context for
whatever is desired;
it binds one only to
selfish interest. But
making a promise
binds one to someone
else's future. If the
promise is serious
enough, one is
brought to it by love,
and in awe and fear.
Fear, awe, and love
bind us to no selfish
aims, but to each
other. We are speak-
ing where we stand,
and we shall stand
afterwards in the
presence of what we
have said.*

— WENDELL BERRY,
STANDING BY WORDS

My name is Lucas Stewart, and this is my brother Jon. We're here to give a kid's point of view. Jon and I are brothers in a big family. I've been a foster brother all my life! Many people don't understand why my family is different, and why it's O.K. to be different. Let me tell you some of the good things and the bad things, from a kid's point of view!

First the good. Being in a big family, we are never bored. There's always lots to do and lots of kids to play with. I learn new languages like signing and eye-gazing. I have learned that kids have different needs - but it doesn't matter - they are still kids!

I had a brother and sister who died, and I learned about death and it being a part of my life - and I can always remember the good times we had and how much we loved each other.

And now the bad. Baby-sitting is difficult because most sitters have no experience with handicapped kids, and I have to show them what to do! Getting out with both my parents at the same time is hard because sitters are hard to find and cost a lot. And it takes us a long time to get ready to go out because half our family needs a lot of help. But we always have fun once we get going!

I'd like everyone to know that I think that kids in institutions would have a better chance of learning more in a family, and plus then they would have a family forever.

Thank you, Lucas

Stewart

4.

Re- Visioning Collective Responsi- bility

In 1866, Samuel Gridley Howe was invited to give an address on the occasion of the laying of the cornerstone for a new institution for the blind in Batavia, New York. In his address, Howe laid down a set of principles regarding services to people with disabilities which might well serve as an excellent guide for the 1990's. It is indeed tragic to find ourselves 125 years later just beginning to learn the importance of the principles he articulated so courageously. His address states in part:

The human family is the unit of society. The family, as it was ordained by our great Father, with its ties of kith and kin; with its tender associations of childhood and youth; with its ties of affection and sympathy; with its fireside, its table and its domestic altar — there is the place for the early education of the child. His instruction may be had in school; his heart and character should be developed and molded at home...

We should be cautious about establishing such artificial communities, or those approaching them in character, for any children and youth; but more especially should we avoid them for those who have natural infirmities, or any marked peculiarity of mental organization....

They depend more than ordinary persons do for their happiness and for their support upon the ties of kindred, of friendship, and of neighborhood. All these, therefore, ought to be nourished and strengthened during childhood and youth, for it is then, and then only, that they take such deep root as to become strong, and life-lasting.... The home of the blind and of the mute should be his native town or village; there, if possible, he should live during childhood and youth; there he should form his friendships; there, if he comes to need special aid, it will be given most readily and fitly; and there his old age will be cherished.

Beware how you needlessly sever any of those ties of family, of friendship, of neighborhood, during the period of their strongest growth, lest you make a homeless man, a wanderer and a stranger. Especially beware how you cause him to neglect forming early relations and affection with those whose sympathy and friendship will be most important to him during life....

- Samuel Gridley Howe, 1866

ON DREAMS, GIFTS, AND SERVICES

BY JUDITH A. SNOW

When I was in school, one of my fellow students was an Olympic diver, a veteran with many medals. My community seemed to know just what she needed to continue to be both a gifted diver and one of our classmates. We knew that she needed access to the swimming pool at 5:30 a.m. every morning; she needed tutoring to keep up when she travelled; she needed friends, and recognition, and she needed to graduate along with the rest of us. She needed a local volunteer sports club and various national and international organizations to maintain her opportunities to dive.

Now, a student with disabilities needs exactly the same sort of opportunity and structure to participate along fellow students. But in our world it is thought to be fun and exciting to support the dream of an Olympic diver, and a burden to support a child with disabilities. The way we view giftedness makes all the difference.

Once my father told me that in ancient China, very rich or powerful families would bind the feet of young girls. As these girls grew up they became unable to walk more than a few hobbled steps. If a woman were truly rich and powerful she would give up walking altogether and she would grow her fingernails until her hands were heavy and functionless. She would be carried about all day by slaves who bore her chair and her cushions to support her hands. They would feed her and look after her every need.

What interests me about this story, and the reason my father told it to me, is that my body works as if I were one of those ancient Chinese ladies. I get around in a motorized wheelchair and a van adapted with a wheelchair lift. I type on a computer with a breath control that reads my puffs and sips as Morse Code and translates the code into letters and computer controls. Otherwise my every physical need from eating to driving the van must be met by a team of attendants. These attendants cover a 24 hour shift and their wages are funded with government dollars.

One critical difference between my life and that of an ancient Chinese lady is that she was considered to be of value in her society just because she was there. Her mere presence as a symbol was of more value than any other potential contribution she could make, and she was supported and shaped through great suffering to become that symbol.

In my world, people are valued according to their conspicuous function and activity, and few things are viewed more negatively than disability. People with apparent disabilities are usually subjected to endless efforts to "cure" them or educate them out of their differences. All the time this is

going on they are segregated out of everyday life and denied ordinary, obviously desirable experiences such as work, play, income, friends, and intimacy.

In many parts of our society, people with disabilities are selected for death. Today doctors regularly use amniocentesis to discover Down Syndrome or Muscular Dystrophy (which I have), or Spina Bifida, and recommend abortion for this reason only. Others are denied ordinary health care or important services, leading to death from treatable infection, starvation, etc.

How can one society value one physical and mental state so highly that people would put their children through torture to ensure they attained it, while another would value the same state so negatively that it would, if possible, kill any children who happened to develop it?

Services that are directed toward people with disability are usually driven by motives that are based on charity, therapy or protection.

In contrast, ordinary citizens receive services which are driven by the understanding that the citizen desires to be and must become an active participant in society, playing some role in keeping regular daily life going. Thus ordinary services attempt to maintain the participation of people, keeping the roads open, fuel in cars and busses, food in stores, information universally available, water on tap, sewers working and children being introduced to the meaningful symbols of the culture. Although not everything runs smoothly all the time, and one can always imagine better ways in which these things could be done, it is clear that the basic purpose of ordinary services is to nurture the capacity of ordinary citizens to offer their gifts to the community.

Many people labelled disabled have discovered that they can find no automatic place for themselves in society. Pushed beyond the margins, they have found the capacity within themselves to dream and build something new. They, and their friends, *must create* the very opportunities they require.

Suppose that the person with a disability is the bearer of a deep and creative dream, and that the dream has meaning that can be conveyed to you. Suppose that the dream has the power to enrich your life and the lives of others - that it is a dream we all need - one that would strengthen and enrich our families, schools, communities, churches...

Bend your will and your inner and outer ear to listen to this dream. Walk into the daily activities and environments of life with this person, as dream and reality mix in a creative dance. May you rejoice in all that you create together.

*To speak and not
to punish. To speak
and not to condemn.
To speak in order to
educate and enrich,
not to repudiate and
humiliate. To speak
and to cure, not to
hurt and wound:
Rebbe Wolfe of
Zbarazh believed in
using language ex-
clusively on behalf of
man, never as a
weapon against him.*

*- Elie Wiesel,
Somewhere a Master*

TEN THOUSAND THINGS

BY DAVID WETHEROW

A friend of mine, who got Polio in 1953, has recently begun needing more physical assistance (we're all getting older). At this point, he needs three things: help to get in and out of the bathtub, occasional transportation, and help with the heavy cleaning jobs in his apartment. He has to access three separate service bureaucracies to get these things done, and he reflects on how much distortion this creates in his life. If his home care attendant is behind schedule, he misses a morning's work, because the transportation service will only pick him up at predetermined times. On cleaning days, he has to remain in his apartment (and miss another morning's work) because program regulations won't allow the cleaner to enter the apartment without someone else being there. He often has to leave meetings, or movies, or concerts early because the transportation service is on a locked-in schedule.

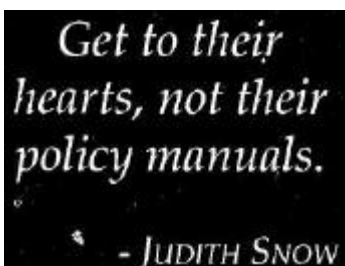
"You know," he said to me, "it would be so simple if they would just give me the money. I could hire my neighbor to get me in and out of the bathtub, contract with a commercial cleaning service to clean my apartment when it didn't throw my schedule out of whack, and call a cab when I needed transportation. Hell, I would do the management for free."

Another friend, who was listening to that conversation, said "It's like there's some poor guy dying of thirst. We know that he needs water, so we dip into the tax base, and come up with eight ounces of clean, cold water. Then we pour this glass of water down through all these layers of bureaucracy, and a whole lot of it sticks to the sides. What finally comes out of the system is about an ounce-and-a-half of brown, gucky fluid, and the guy is made to feel lousy about asking for water in the first place. There's got to be a better way."

Imagine what your life would be like if you had to depend on bureaucratized service systems to meet all of your everyday needs. What if you had to depend on a residential service program for your housing, a transportation program for getting around, an employment program for your job and your children's jobs, a recreation program for your leisure, a socialization program fun, an advocacy program for friendship, *ad infinitum*. Think about what it would be like to compete with your neighbors for access to all of these programs, or what talk to a manager every time you wanted to change things. Imagine how many managers there would be!

But we don't live like that. Many of the things that are most essential in our lives are given freely — friendship, love, a sense of belonging. As Judith Snow points out, many others are provided as part of the basic infrastructure of our community. As for the rest, we use our personal and family and community resources to discover our directions and create our own solutions, day by day.

In a classic Family Circus cartoon by Bill Keene, the mother



Get to their
hearts, not their
policy manuals.
- JUDITH SNOW

Back home, after services, Rabbi Naphtali of Ropshitz fell into his chair, exhausted. His wife asked him how it went. Were there many people? Yes, I believe so. Did you succeed in convincing them? With a smile, Rabbi Naphtali answered: I only half succeeded, and that isn't bad. As his wife seemed puzzled, he explained: I convinced the poor to receive, but not the rich to give.

*- Elie Wiesel,
Somewhere, a Master*

is changing a baby while his older brother asks, "If babies don't come with instructions, how do mommies know how to work them?" Well, she *does* know. All of our mothers knew. Our families, and friends, and community *knew* what we would have to learn, how we would grow, and who would have to care about us so that our lives would unfold "as they should". Our lives emerged in the context of love, and hospitality, and expectation, and a deep and so complex understanding.

How can we bring this simple reality 'home' for people who have lived out their lives in the context of programs? How might we provide public support so that the vulnerable person remains a full member of the community, and the community remains competent, confident, and committed to have that person's life unfold "as it should"?

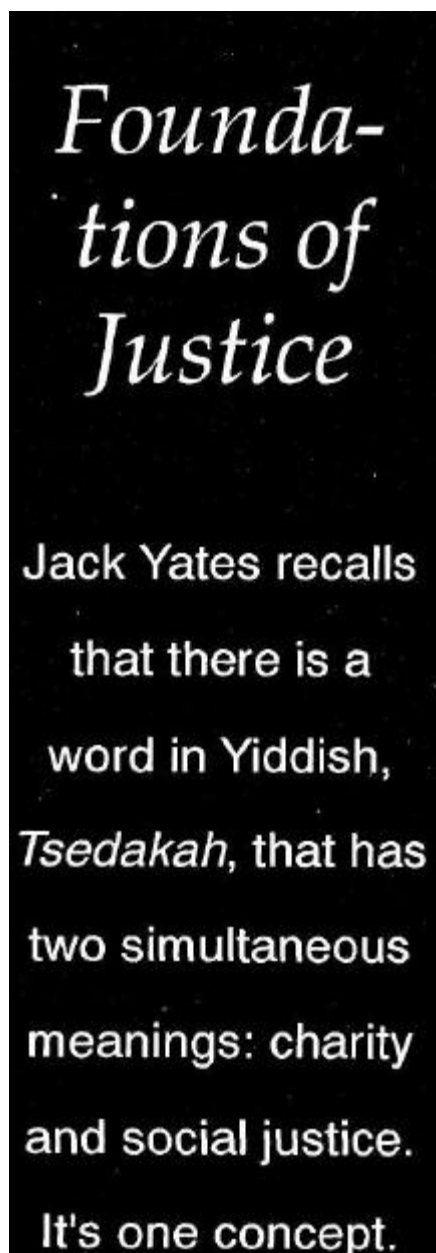
In an ideal world, disability would not make people vulnerable (remember the story in Everyone Here Spoke Sign Language). Unfortunately, in our culture, people with disabilities are particularly vulnerable to "falling out of the boat" of community -- to being economically and socially marginalized. Families and friends can overcome many of these vulnerabilities through the act of life-sharing. But they need encouragement and support, and they may need help in rediscovering their own capacity for hospitality, for creativity, and for care. Perhaps rather than a proliferation of services — the "ten thousand things", *three* things would be helpful:

First and foremost, a level of personal income which would ensure a standard of living equal to that to which valued, ordinary citizens aspire;

Second, supplementary income to enable the purchase of needed specialized supports (e.g., equipment, attendant care), including the possibility of income replacement for care-giving family members; and

Third, accessibility to and adaptation of generic education, transportation, communications and health care services.

The possibilities are endless: Convert existing service entitlements to income. Make future public investments meet the test of how effective they are at supporting, rather than replacing, the care of family, friends, and community. Invest in subsidized adoption. Pay attention to Ed Roberts and the Independent Living movement. If "the system" is in need of transformation, invest in transformation, instead of the ten-thousandth-and-narf service. Hold a contest to see how many ways people can think of to reduce the "transaction costs" of bureaucracy and convert the savings. Simplify.



In Foundations of Justice, Robert Veatch reflects:

In order to deal with these questions it will be necessary to summarize succinctly the central premises, the faith commitments, upon which the Judeo-Christian version of equality is based....

It is perhaps overly ambitious to summarize the core faith commitments of three thousand years of very complicated history in three basic premises, but, with admitted oversimplification, that is what we will attempt... The key premises are contained in what theologians will recognize as the doctrines of God, creation, and stewardship.

First, God is absolute, the ultimate center of value in comparison to which all humans are equal in their finitude.

Second, the earth and all that is in it was created and given as a gift to the community such that there never was a time when there were unowned resources in the state of nature waiting to be appropriated by anyone clever enough, ambitious enough, or powerful enough to take them.

Then, finally, because the resources of the world are in some critical sense a common possession of the community and because all are bound together as equals in that community, people individually and collectively bear within limits a responsibility to see that those resources are used to recreate or maintain the equality that is the appropriate relation among humans.

Robert M. Veatch: The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality, 1986; Oxford University Press, New York; p. 66

LEADING EDGE LEARNING: An Integrated Approach to Policy Analysis

Learning at the leading edge of innovation and new problem areas is an effective way to speed up vision finding and error correction for a system. The issue in organizations is not to avoid making errors, but to make errors fast enough to learn from them. If policies are a hypothesis, rather than the answer, then we must pay attention to our most recent policies and learn about what is working and not working.

Aaron Wildausky, *Speaking Truth to Power: The Art and Craft of Policy Analysis*, 1979

The creation of coherent units of turned-on people who engage in intense experiments with quick feedback facilitates the ability of a system and innovative programs. These are pragmatic, creative teams who wander around far away from central headquarters, and they are far more successful than any other kind of business task force.

Tom Peters, *In Search of Excellence*, 1983

Effective organizations are those that create numerous integrative mechanisms which counteract the negative effects of segmentation. Decentralized structures are most in need of integrative processes. Integrative structures and processes provide forums for members throughout an organization to listen and learn from each other, and find meaning and knowledge in the collective awareness and experience of the whole.

Rosabeth Canter Moss, *Changemasters*, 1983
William Ovchi, *The M Form Society*, 1984

The interface between the human service system and the community represents the most fruitful arena for new resource development and discovering mechanisms that enable "the community" to have more of a part in supporting its members who have disabilities. It is essential to focus on this domain in order to reverse the long-term effects of community "addiction" to the service system, as well as discovering new resources and new forms of supporting people with severe disabilities.

Donella Meadows, *Groping in the Dark: The First Decade of Global Modelling*, 1982

It is essential to identify problems and discover approaches to dealing with them as a part of the same process. Creativity consists of finding a problem about which something can be done - the solution is part of defining the problem. The way to solve large social problems is to keep them small. Effective policy analysis is an activity that creates problems that can be solved through a process that combines social interaction with intellectual cognition. The key is having forums and processes that facilitate this type of process.

Trevor Williams, *Futures We Are In*, 1982
Garth Morgan, *Beyond Method: Strategies for Social Research*, 1983

BEYOND NEED: TOWARD A SERVICED SOCIETY

BY:

ANDREW GORDON
MALCOLM BUSH JOHN
MCKNIGHT LINDA
GELBERD TOM DEVVAR
KATHY FAGAN ALICIA
MCCAREINS

CENTER FOR URBAN AFFAIRS AND
POLICY RESEARCH
NORTHWESTERN UNIVERSITY

There is available on many toy counters an unusual and instructive machine. It is a battery-operated five-inch box with a lid and an exposed switch. It is otherwise unadorned. If someone flips the switch to turn the machine on a grotesque hand emerges from beneath the lid with a single purpose: to turn the switch to "off" again so that the machine can sit silently until someone else turns it back "on."

In one sense this is a perfect machine. The hand effectively carries out its mission ~ to prevent any outside interference with whatever is going on inside the box.

Imagine a bureaucracy which is similarly perfect, one which operates only in ways that guarantee its continued smooth operation and does not brook interference from the outside world. Let us imagine further that this box is a service bureaucracy, an organization whose public function is to serve people who need help. The service may or may not require institutionalization. The bureaucracy may be public or private. How would this box bureaucracy be organized if its sole aim were to guarantee its own smooth operation, without any interference or complications?

The task can be broken

down into four major areas:

- 1) the creation of need;
- 2) the management of clientele;
- 3) the control of information and accountability to nonclients; and
- 4) the growth of public perceptions of need.

The Creation of Need

The box must appear to serve not itself but society, and in so doing relieve the public of a major burden. Therefore, a needy class must be denied. The definition must be broad enough so that the potential clientele is greater than the box's capacity to provide service. The boss will then be able to reserve the ultimate right of selection from that needy class, taking care to select those who will least disrupt the system.

The ideal clients would also be those least in need of the service to be provided. A show of effort, a shuffling of papers, and these clients would be perceived by the public as successfully processed.

Ideal clients are also personally powerless and unconnected with assertive outside interests, minimizing outside interference. The aged, the poor, or the children of the poor seem especially well-suited. Since these categories of people are

also the most apparently in need of benign care, they are doubly ideal. Effective public relations requires that some clients who are obviously in genuine need of service be accepted as well. However, should totally disruptive clients be accepted through public pressure or faulty screening, liaisons can be established with other less visible and legitimately coercive agencies to assure stability.

The Management of Clientele

In the perfectly managed box, the clients' needs may sometimes hinder the provision of service. Therefore, the managers of the box first decide what services can be provided without undue inconvenience, and take steps to persuade clients that those are the services they need.

Nonetheless, some clients will criticize the quality of the service they receive, or declare themselves "served" and ready to look after themselves. Clients must be persuaded that their perception of their needs is fallible, that they do not have the training or skill to judge the services they are receiving, and they must never trust their own opinion of whether they are sufficiently served. The language anticipates us. The Latin root of the word "client" is a verb

which translates to hear, to obey. They should be made to understand that they are too young, too sick, too neurotic, or too ignorant to rely on their own judgement. Once the clients are persuaded of their correct needs, the box ensures that they perceive no alternatives to the service the box delivers.

The labels used to define clients must stress their weaknesses and ignore their strengths. Promoting the common understanding that clients are alike only in that they are all deficient inhibits them from recognizing and exploiting their individual and collective strengths.

Clients must not be allowed to contribute to, or even have access to, the records describing their progress. All of their behavior should be suspect, and fit material for manipulation.

A few clients might still display some behaviors disruptive of the daily routine of the box. However, this can be discouraged by labelling as desirable that behavior which assists the smooth running of the service machine, and by treating as deviant those acts which interfere. In fact, unruly behavior can be viewed as symptomatic of the client's need for more intensive services. The box can ensure adherence to that behavior which suits it by a system of rewards, punishments, per-

suasion, and group pressure. If subtle controls do not work the box could employ forms of physical restraint (incarceration), physiological control (drugs), and psychological manipulation (therapy) which further strip the clients of power.

The Control of Information and Accountability to Nonclients

Since the box dispenses kindness, few will question its activities. At its best, the box appears benign to the public, clients, and helpers. However, the box will be required to account to the public for monies spent, services purchased, and services delivered. The public will occasionally demand information about its inner workings and accounts of its stewardship. The solution is to persuade the public that the only people competent to examine the box's operations are those who have been licensed and trained in its specialty; no one else has the skill to appreciate its methods or to evaluate its results. As an additional precaution, it would suggest to those who do not understand its specialized language that the fault is theirs. The box would deny information to those who try to pry further, undermining their credibility by scoffing at their experience, training,

and competence.

It may be necessary in some cases to assure the public, through an apparently independent audit, that the box's services are working. This appearance can be created by and interdependent web of interest, incorporating training institutions, professional associations, licensing bodies, paid evaluators, and professionalized funders of evaluations. These symbolic interests, rooted in a common system of values, will preserve the illusions of independent accountability.

The professional helpers can also create organizations appearing to regulate professional conduct while, in fact, bearing down heavily on colleagues who would challenge time-hallowed procedures. The scope of these professional organizations guarantees influence at all levels of government, insuring maximum public finding, and minimum accountability.

If the box was still required to submit to external inspection, it could turn even this demand to an advantage. It agrees to evaluation of its methods and systems, never its outcomes. The box will answer questions which are consistent with its own goal of smooth functioning. It will thwart and otherwise circumvent questions which entertain the alternative value of maximizing clients'

well-being.

Persistent outsiders may insist on evidence of successful service. Placebo recoveries, spontaneous remission, and healthy clients who have not been harmed provide examples of putative successful treatment. The box's monopoly of the skill to diagnose both needs and successful outcomes increases the likelihood of acceptable evaluations.

For any unconcealable failures ~ clients whose disability the box has not helped, has exacerbated, or has even created — the appropriate strategy is again to turn a possible embarrassment to an advantage. The box can assert that the problem is caused by a lack of funds, citing high client-helped ratios, low salaries, poor technology, and insufficient research. The operating assumptions of the box should never be questioned; rather, the public must understand that what is needed is more of the same.

The box can also persuade the public that what it perceives as failures are really successes. Whatever now troubles that "failed client" is minor compared to the problems that the clients had before or would have had without the box's professional intercession.

Another approach to perceived failures is to shift the blame to the client. The

box can explain that the clients were beyond help when treatment began. Genetics, neighborhood, or family constellation guaranteed failure. If the clients are poor, minorities, or dispossessed, the public usually will be prepared to accept these explanations.

If all else fails, the box can suggest that it was not allowed enough control to enable it to help the client.

Growth

If there is any untidiness which remains in this system, it is caused by the constant need to react to nonclient groups. This problem must not be dealt with by taking a defensive position. Rather, the service bureaucracy should tackle this irritating remnant by a concerted effort to expand its hegemony. By expanding the number of clients, the number of nonclients who are potentially disruptive diminishes. The box must enlarge the stream of potential clients and demand more resources for its increased responsibilities.

To achieve this end, the box should first increase control over its present client. This can be accomplished by insisting that treatment commence at a less advanced stage of the problem and by requiring longer term care. By promoting an awareness

of the systematic nature of the problem, helpers can extend their care and attention into new areas of their clients' lives.

The policies of reformers who criticize the accepted forms of service can also be used to widen the net. The critics say that giving help to a single person outside the context of his family is self-defeating. Therefore, the entire family is invited to therapeutic sessions, involving them all in the problem. Some critics may also decry the practice of placing people in institutions and insist that clients be served in their own houses. The box should accept the criticism, so that the client's parents, brothers, and sisters may also become clients. Beyond the immediate family, others who are not obviously sick are susceptible to the "crises" of childhood, adolescence, middle age, and old age. The seven ages of man are replaced by the seven crises of man. The meaning of life is defined by a series of crises, and each attracts its own band of helps and institutions.

The concept of need has now been stretched to its limit, and there are still people outside the box. The helpers must therefore persuade those remaining outside that unless they, too, are given help they will not retain that enviable position

bureaucracy to justify its existence in order to survive and expand. Indeed, the client will have "forgotten" that there should be a relationship between need and service. They will use the box because it is there. They will feel incomplete, unreal, and lacking, not because they have a need, but because they cannot get into the box.

As a result, the issue of equity is defined as the right to enter the box. Finally, the law will be inverted, with equity defined as the right of the box to encompass all.

We trained very hard, but it seemed that every time we were beginning to form up into teams, we would be reorganized. I was to learn later in life, that we tend to meet any new situation by reorganizing; and a wonderful method it can be for creating the illusion of progress while producing confusion, inefficiency, and demoralization.

*- Petronius Arbiter,
69 A.D.*

THE INTRAPRENEUR'S TEN COMMANDMENTS

1. COME TO WORK EACH DAY WILLING TO BE FIRED
2. CIRCUMVENT ANY ORDERS AIMED AT STOPPING YOUR DREAM
3. DO ANY JOB NEEDED TO MAKE YOUR PROJECT WORK REGARDLESS OF YOUR JOB DESCRIPTION
4. FIND PEOPLE TO HELP YOU
5. FOLLOW YOUR INTUITION ABOUT PEOPLE YOU CHOOSE, AND WORK ONLY WITH THE BEST
6. WORK UNDERGROUND AS LONG AS YOU CAN - PUBLICITY TRIGGERS THE CORPORATE IMMUNE MECHANISM
7. NEVER BET ON A RACE UNLESS YOU'RE RUNNING IN IT
8. REMEMBER IT'S EASIER TO ASK FOR FORGIVENESS THAN FOR PERMISSION
9. BE TRUE TO YOUR GOALS, BUT BE REALISTIC ABOUT THE WAYS TO ACHIEVE THEM
10. HONOR YOUR SPONSORS

Hewlett-Packard

5.

Relationships: Family & Friends

IT'S ABOUT RELATIONSHIPS

EXCERPTED FROM AN ESSAY BY MARSHA FOREST

To the old ones of my childhood who taught me the most important lesson of all: That I did not need to be perfect to be loved. That no one does.

- Alice Walker, Introduction to *To Hell With Dying*,
(New York: Harcourt Brace Jovanovich, 1967).

The previous message in Alice Walker's beautiful children's book *To Hell With Dying* speaks volumes to me personally. All I really ever wanted in my own life was a group of people around me and especially one central person in my life who would just love me totally as I am.

For years the people in my own life and family said they loved me, but I felt they never really knew me. The men in my life said they loved me, but all the while they tried to change me, criticize me, or pick at me. I tried and tried to be perfect and I felt worse and worse.

I was successful at work. Nobody knew when my heart was breaking. I thought this was good. I could control my feelings. I'd be tough at work and crack up at home. I, who love life so dearly, thought about death, dying, suicide - I lost weight, I cried in hidden places.

And then at the age of 34 something snapped. I visited another culture in Asia and the distance from home and the strangeness of the land and people opened my heart and soul. I decided I wanted to fly - that is, to be free of the past and I opened myself to love.

At this very time of change I met two people who changed my life both personally and professionally - Jack Pearpoint and Judith Snow. They are both entwined with me on this journey to create a world where people are loved for who they are and cherished for the gifts they have to offer.

I have started this essay with a bit of my own journey as I feel it is important to stress the universality of my theme and that universality must begin with myself.

I am not at all interested in disability, mental retardation or special education. I am, however, passionately interested in being part of building a just and human society where each

human being can live in dignity and have his/her needs met - whatever that may involve.

THE CHALLENGE

Bringing people who have been excluded on the basis of race, class, sex, or handicapping condition back into the mainstream is an exciting, controversial and dynamic process for it challenges the basic assumptions of each of us and at the same time introduces us to new ways of thinking and seeing.

I was not born thinking like I do today. I accepted the notion that people with disabilities needed institutions, special care, special education, special housing. I, however, was open to being challenged (at times yelled at) by friends who saw another way.

As I got to know my friend Judith Snow and as I became involved in her struggle to get out of a chronic care nursing home, I learned about the reality of life for most people with disabilities. I was angry and disgusted at the injustice of it all.

Judith was my friend. How could she stand to live in a prison - or as she called it a "concentration camp". How could she put up with all that disrespect and pain? She had two choices - live or die.

I learned that when you

love people as they are, you stand with them and fight with them and laugh and cry with them. You don't try to change, adjust or cure them. You want the best for your friends and in return those friends want the best for you.

You won't take the "least restrictive environment" - you want the BEST, the MOST. You never want the least for those you love.

But the attitudes of wanting perfection start at birth (or today even before with the trend to wipe out all children with down syndrome through amniocentesis). Just this week a friend of ours gave birth one month prematurely to a three pound baby who is said to be "profoundly" brain damaged. She was supposed to die. But this tough little girl didn't die.

The advice given by physicians to the family in 1989 in a supposedly progressive hospital in Vancouver, British Columbia is "don't bond with the baby - she will probably die, or at best be a burden to you for the rest of your lives."

The young couple are told daily by medical experts and family members not to LOVE their child. What kind of world is this where we tell parents not to love a child? No one has any idea what this baby will become. She may be dead in a week or live to be the oldest woman

alive. No one can predict.

The message NOT TO LOVE is insane, mean, cruel, horrible. Love the baby if it's perfect. Hate the baby if it's imperfect in any way. Love me if I live the life you want. Hate me if I am not perfect in your eyes. Throw me away if I am different. Get rid of me if I am unique.

The implication is horrible - I will love you as long as you are perfect - but if you are in a car accident, if you lose a leg, if you become hard-of-hearing, and if you become old and unattractive then I will stop loving you. I will put you away and I will reject you.

It starts in the hospital - it too often ends in a nursing home.

Luckily most families fall in love with their babies and love them despite the best advice from doctors - (these great fortune tellers of the future of a newborn).

And so the child is loved and welcomed to the family but then the child hits school age and the curtain drops again.

The child is not welcomed in his/her neighborhood school - rather he/she is sent to that SPECIAL place where SPECIAL people do SPECIAL things to the SPECIAL person and in reality absolutely nothing special is going on at all. Segregated schooling is a holding action until adulthood when more

SPECIAL places called group homes or sheltered workshops or day programs do more of nothing special and the only un-special place that child will ever end up in is the regular cemetery where he/she is as we all will be one day - dead.

But while we are alive we have the right to live, to love, to have fun, to make mistakes and to fly in our own direction with our own friends.

A TRUE STORY

About a year after May had been fully included in Grade 7/8, she and some of her friends went to a neighborhood school yard to play. Some Grade 8 boys from the other school started teasing a child in a wheelchair. The girls, smaller than these boys, hesitated for a moment before they took on these bullies.

Amv. the leader of the girls told the boys to stop. They didn't. She persisted. Amy, was by this time, furious. When they got back to school they stormed into the principle's office and wanted him to take immediate action against these bullies at School X.

I visited the class soon after the incident and asked everyone to tell me what had happened. A lively debate ensued about whether Amy and her friends should have

gotten involved.

Some of the children felt Amy had been "foolish," "stupid," "naive," etc. to take on boys much bigger and stronger than herself. "She could have been hurt," some felt.

Amy was indignant. "You have to stand up for what's right," she argued. Her friends (including May) chimed in arguing for what was right and decent according to them.

I widened the conversation by asking what they thought the role of the students in South Africa today is and indeed, what happened in Nazi Germany when non-Jewish children befriended Jewish children.

The room was in an uproar of incredible philosophical debate. I was struck that the level of discussion was far more sophisticated than among several of my graduate seminars at the university. The discussion was thoughtful, deep and passionate.

The issue in the Waterloo Region has gone far beyond "integration" and ranges into the real meaning of community, social justice and integrity of each individual. I was impressed, moved and thrilled to see this ordinary group of working class children handling the "big" ideas that we so infrequently allow to discuss. This was beyond cur-

riculum guides on individual differences. This was REAL. This wasn't an abstract discussion about wooden puppets with different disabilities - this was about the meaning of life itself.

CONCLUSION

Working with hurt and rejected people is not always easy. It takes time, energy and the power to love. There are no simple answers except that we must do it because if we don't, the human cost to us and our children will be enormous.

The greatest diseases in North America today are loneliness and meaninglessness. Bringing back the least powerful into our schools is an incredible antidote to the consequence of these diseases - suicide, alcoholism and drugs. Helping one another is a beautiful thing, but it's not something you simply talk about - it is something you do.

About eight years ago Sherry arrived at our home when we had just discovered we could not have biological offspring. Through a series of strange events, this lost and lonely teenager came through our front door not to leave again for many years.

Sherry had been neglected and abused by her father, and her mother was deceased. She trusted no one, most of all herself. She tested my very soul.

and Vanessa and Andrea and Barb and most of all my dear, sweet Sarah, my living, breathing link with the future.

I wasn't defensive. I didn't yell or cry. I spoke with my heart and each word seemed to bring with it some healing.

People were listening to me - me, this useless nothing that the social service system saw fit to abuse and abuse, and who wished would just go away and die, because I had nothing to offer, no gift, no nothing.

Tonight this nothing just became something. For the first time in sixteen years I know I am going to make it. For sixteen years I still accepted their vision of me. Now finally, after sixteen years, I am putting all the labels they put on me where they belong - in the garbage! I am going to make it with the little help from my friends. I am going to put the power back where it belongs - with me -with us!

Tonight I sit here overflowing with love and gratitude for all of you and all you have done for me -for your friendship and caring. For sixteen years I have been walking around with a knife stuck in my back - you have all helped me to pull it out. The sharp pain is subsiding, slowly the skin will regenerate and the scar will fade - never completely though. But now what I will remember is not just the wound but the friends who helped me heal.

This is our victory too and I want all my friends to share it

with me. I hope someday to make a difference in somebody else's life like you have all made in mine.

I hope my beautiful Sarah and her children and friends will grow up without ever knowing the awful pain of being excluded and of being utterly and totally alone. I want to help build a loving community out there that will embrace every child. I want the community to see the lovely gifts all our children have to offer.

If only all children and parents could receive the love I feel today then the world would truly be a better place for us all.

Thank you all. I love you.

*Sherry March,
1989.*

*This is the true
joy in life, the being
used for a purpose
recognized by your-
self as a mighty one...*

*I am of the opin-
ion that my life
belongs to the whole
community, and as
long as I live it is my
privilege to do for it
whatever I can.*

*- George Bernard
Shaw*

FOR THE NEW FAMILY

Six years ago, I got a telephone call from my father, telling me that my brother and his wife had a newborn child. Dad's voice broke as he told me about her condition. The baby had a rare birth defect known as *craniostenosis osyndactaly*, or Apert's Syndrome, meaning that her hands and feet had not developed fully, and that the bony plates that made up her skull were fused together. Premature fusion of these plates creates growth problems in all of the other bones in the face and skull.

I spent the next few days in a medical library, reading whatever I could find out about Apert's syndrome, and flew to California to see if I might be able to help.

At that time, I had been working in the field of disability for about ten years. On the plane headed west, I thought about the 'training' I would offer them when I arrived — ten years' worth of normalization training, conferences, site visits, evaluations, all rolled into a five-day visit. But when I met my brother and sister-in-law, I realized that they were going to be able to *hear* only one or two things. They were in

deep shock. Feelings of sorrow, and fear, and guilt overwhelmed them.

One thing that I have learned since that visit is how important it is to simply *listen* — to allow the full expression of feelings and fears, and to acknowledge their legitimacy. They may not be the most helpful feelings in the long run, but they are overwhelmingly true at the time. And any attempt to deny them will stop communication at a time when communication is needed most.

But beyond the need for a compassionate listener, what is the bottom line? If I could only communicate one or two things, what were the essential messages? What are the organizing ideas that can help the family over the long haul? I believe that they are the following:

First, the feelings of fear, pain and sorrow are normal, especially in the light of how we have been prejudiced against people with disabilities. It is important to recognize the legitimacy of these feelings, but it is also important to move beyond them. *The birth of a child with a disability does not mean that a "promise has been stolen" ~ from the parents, or the child, or the community.*

Parents convey powerful messages about the identity, place, and value of this child. One of the deepest wounds that can be experienced by

people with disabilities is hearing the message that their very existence is a tragedy, that they are a source of anguish to their families, and a burden to their communities. It is crucial to turn these messages around. (One way of beginning to do this might be to imagine *adopting* this child ~ making a conscious commitment to be a gift to the child, to celebrate his life, and to discover his gifts, and share them with the community.)

And second, besides the love of her family, *the one thing that will have the greatest impact on the quality of this child's life will be the presence of a circle of friends (both children and adults) who know her, who love her, who are not afraid of her disability, who see themselves as being part of her future, and see her as being part of theirs.* Those friends can be community for her. They can identify her gifts, and offer opportunities for the expression of those gifts. They can be her friends, so she doesn't have to depend on programs for friendship. They build bridges to other relationships ~ to trusted friends and the associations they belong to. They can support her family. They can be her champions and her guardian angels. They can answer the question: who will care for her if something happens to me? They can create the solutions that she needs.

HOW PARENTS CAN HELP CHILDREN

DEVELOP FRIENDSHIPS

Parents can try a variety of strategies to encourage relationships to develop.

1. Create an environment in your home that attracts kids; make it a fun place for them to get together.

Have snacks available; make children feel welcome to visit or just drop by. Have activities going on that your child and peers enjoy, such as Nintendo, bike-riding, games, etc.

2. Play "detective": Observe very carefully the places where other children in the neighborhood hang out, noting the activities they enjoy, trends in clothing, music, hairstyles, etc.

3. Sign your child up for community groups and activities that involve other neighborhood children of the same age.

Consider scouts, swimming, summer day camps, after-school clubs, church groups, crafts classes.

4. Help your child reach out to children he/she likes.

Make phone calls, invite kids over to watch a video, take several along to the pool, the mall or on a family outing.

5. Be sure your child has a typical routine, school day and lifestyle - minimize differences.

6. Find and model ways for friends to help your child participate ~ even if the participation is only partial.

Demonstrate ways to include your child in games and activities as well as techniques to make your child feel comfortable and safe in new situations. Then let the kids be together.

7. Minimize adult presence and intervention in day-to-day activities.



Let your child be directly involved with other children without an adult always being right at the child's side.

8. Find a role in which your child can succeed, using his/her interests and strengths in different settings.

9. To keep things moving, invite two friends at a time over to play with your child.

10. Speak up when you need assistance or ideas to help your child develop relationships.

Ask people at school, family friends, brothers, sisters or neighbors for support.

11. Become involved and visible with your child in neighborhood and community activities.

- PEAK PARENT CENTER, COLORADO
SPRINGS, COLORADO

ON BECOMING A MEMBER OF THE COMMUNITY

BY GEORGE DURNER

Among people whom I know in North America and Western Europe there is a growing realization that we are placing men and women with mental handicaps and other disabilities into the mainstream of society and asking them to keep their heads above the water while supplying them with only a minimal amount of expertise and support. We acquaint them with some of the fundamentals of societal swimming and then tell them to jump in and go to it. They lack the

most important survival precaution ~ someone to hold and support them while they are learning, or when they become tired, or when the currents become too difficult to manage.

Perhaps we forgot too easily how dependent we are on the relationships we have with others. Often we are not conscious of them until they are threatened, or we actually lose them. Relationships provide us with vital social and work-related connections. They enhance our life possibilities. And most important of all are those relationships in which we are simply loved and valued for ourselves, regardless of our performance. These relationships become real safety nets in our lives. The reality for many of us is that we will be "caught" if we start to go under. There are friends, husbands, wives, relatives, etc. who will not only pick us up and bandage our scrapes after an unsuccessful try, but will also re-affirm our self-worth and encourage us to risk once again. This network of supportive and affirming human relationships sustains us in our everyday lives and enables us to enter into the uncertainty of new experience.

Sometimes it appears that we have unintentionally created obstacles that block

friendships-those special relationships of the heart. Too often it seems that we have set up staff/client, teacher/student, care-giver/patient relationships in people's lives. These supports may be important, but they will not answer the more fundamental need for a caring friend.

We have placed people in homes that are not really homes but rather training centers, schools, and miniaturized institutions. It is important that we become more sensitive to the basic human need that people have for a true home - a place where one can relax and have a sense of peace and security; a place where one is allowed to escape for a moment from the stresses and demands of the world outside; a place where one belongs simply because it is home. We should not find ourselves surrounded by our teachers, trainers, or people called "staff" in our home. Home is where people accept us and value us because of who we are, not because of how we perform. Perhaps we are trying to do too many things for people under the same roof. That is always the case in institutions. The result is that we lose the space, that sacred space, called home where relationships are held more important than anything else.

FROM BEHIND THE PIANO



From Behind the Piano, Jack Pearpoint; 1990; 136 pp.; **\$10.00** CDN from: Inclusion Press, 24 Thome Crescent, Toronto, Ontario, Canada, M6H 2S5; **\$10.00** US from: Expectations Unlimited, P.O.B. 655, Niwot, Colorado 80544.

Jack Pearpoint has written an honest and enthusiastic book about his friendship with Judith Snow and the discoveries that they have made on their journey together. They have been pathfinders — spotting landmarks, illuminating potholes and identifying lessons which need to be learned along the way.

What the book makes brilliantly clear is that Judith's experience of shaking off disability, "a version of myself which never was myself", ranks in historical importance alongside many other heroic freedom struggles.

The book is not about disability. As Judith says, "It is more a matter of creating the world in which I can be myself with my friends. We have to create the language, the vision, the structures and the relationships. We create the meaning. All that so we can be ourselves."

Jack and Judith's twelve-year friendship began when Judith



INCLUSION PRESS

THE JOSHUA COMMITTEE - FROM CIRCLES OF FRIENDS, BY ROBERT ANT MARTHA PERSKE, REPRINTED WITH PERMISSION OF THE AUTHOR:

was living in a chronic care geriatric ward. Her health was deteriorating because of the inability of medical and social services to meet her needs. Judith had tried to pursue life as a member of the staff at York University but her "placement" in a nursing facility made this increasingly difficult. She frequently missed meals because the hospital refused to alter her "feeding" slot and she suffered from water retention from not being allowed to go to the bathroom regularly.

Jack became the "administrative genius" (Judith's words) behind an evolving community of support which was precipitated into action when Judith collapsed after escaping from hospital. She had decided that dying on the street was a better option than dying on a geriatric ward in an institution. Her friends and colleagues decided they wanted her to live.

Judith's fear of abandonment, the dangers of dependency and the dilemma of creating expectations that might not be fulfilled are key considerations in the book. The book charts the fight for Judith's survival in intimate detail, mapping out a complex range of issues, topics, emotions, difficulties and achievements.

At the beginning of 1990, two important developments demonstrated both her strengths and her vulnerabilities. An announcement by the Ontario

Ministry of Community and Social Services of a new program of attendant care was a tribute to the 20 year campaigning efforts of Judith and her friends. But the news that Judith's employers proposed abandoning their role in her funding network — a financial support system which had been painstakingly and precariously put together in the absence of adequate official arrangements — meant that her life was in jeopardy.

Judith was being discarded for obscure, unstated reasons of bureaucratic convenience. She was [administratively] messy and hard to make neat and tidy. This is precisely the history of human services. No one meant to do harm. However, ignorance and lack of careful attention once again put Judith's life on the line. It was another terrifying symbol of how institutions and systems, no matter how caring, can hurt people".

In the end, John O'Brien has comforting words about how to come to terms with our inadequacy and human frailty in attempting to solve seemingly overwhelming problems. In his "afterword" chapter, he reminds us that the root meaning of the word company is nourishment and mutual protection, and that it was in company through shared meals and shared work

that Jack and Judith's friendship slowly grew:

"We don't have to be friends all at once. We don't have to trip ourselves up trying to will something that only comes spontaneously. It's enough for us to choose to faithfully share daily work and daily bread".

- LINDA SHAW
CENTRE FOR STUDIES ON
INTEGRATION IN EDUCATION,
LONDON, ENGLAND

The essential story is not about the events, strategies, or interventions; it is about beliefs, feelings, and attachments that are powerful enough to shape the environment. It is not about humanitarian giving; it is about mutual sharing. It is about the power of common decency, and above all, it is about simple friendship.

I have reviewed many books, some that I've loved and some that I've hated, but they all fit a general pattern that made their review a predictable exercise. This book does not, and reviewing it is like trying to review a child's laughter or a summer afternoon. There is something wonderful in the experience, but it defies telling. It leaves the reader refreshed and open to living their own story.

- DICK SOBSEY
UNIVERSITY OF ALBERTA

CIRCLES OF FRIENDS



Circles of Friends; People with Disabilities and Their Friends Enrich the Lives of One Another; Robert and Martha Perske; 1988; 94 pp.; **\$10.95** (US) from: Abingdon Press, 201 Eighth Avenue South, Nashville, TN 37202; or **\$11.95** (CDN) from: Welch Publishing Company, 960 The Gateway, Burlington, Ontario, L7L 5K7 Canada

In this warm, sensitive collection, Robert and Martha Perske offer true stories and issues to ponder, concerning friendships between people with disabilities and ordinary citizens. They show how these circles cut across age groups, generations, and races, and how the hearts and

worldviews of everyone can be enriched. The emphasis here is on pure and simple friendship.

?

Outgoing and vivacious Tanya appeared to be a kid who might someday fly with eagles, while Shawntell's distinctiveness came from a long string of deficiencies which professionals had stamped on her as if she were a package damaged in the mail - "severe profound mental handicap," "cerebral palsy," "visually impaired," "nonambulatory," "repetitive myoclonic seizures." Those labels stood out so vividly that nobody seemed to notice her many strengths and gifts.





After Tanya's presence in the class for only a couple of days, Shawntell singled her out, crawled directly to her, and reached for her hand.

"I took her hand," Tanya said. "Then I'd slowly help her to stand up. This happened every time she saw me." Tanya, so moved by the compelling way she was chosen as a friend, saw Shawntell immediately as a neat person to know.

"This may sound strange," Tanya said, "but I never really saw her as disabled. She was just one of the kids. Right from the start, I liked her very much."

Although Tanya never thought of herself as teaching Shawntell, they began a daily routine: Tanya entered the

room. Shawntell crawled to her. Tanya took her hand and helped her to stand. Then off the two would go, struggling to walk the school halls. When Shawntell fell down, she got back up and moved on again, with Tanya's support. Just before recess ended, they went back to the classroom, where Tanya braided Shawntell's hair.

"It took two and a half years before Shawntell could walk by herself, Jeff [her Dad] said, "and Tanya stuck with her all that time. Even the teachers and the physical therapists - who fiddled around with her legs every now and then - admitted that it was the walks with Tanya that did the most good."

"Let me tell you what

happened during the summer after their first school year together," Jeff went on, his voice becoming emotional again. "This kid Tanya calls us and asks if she can come over and play with Shawntell. Imagine that, she called us! That never happens in families like ours. *She called us*," he repeated. "And the next thing I know, this kid is coming on weekends with her sleeping bag."

Somehow, when you don't qualify as "normal," you often become the center of a wide array of interventions with words such as these attached to them:

teach	guide
heal	shape
correct	modify
supervise	discipline
prepare	persuade
monitor	coach
evaluate	instruct
manage	enlighten
direct	train
drill	advise
order	control

After an overfull schedule of such relationships, try to sense how you might feel if you suddenly found a friend who

- became attracted to you exactly as you are
- just liked being with you
- and never - repeat *never* - felt the need to fix you.

THE CHOSEN GIRL

BY AMBER SVINGEN



Seven years ago, Faye and Marvin Svingen adopted a child who had spent the first three years of her life in a large children's institution. When they welcomed Amber into their home, they welcomed her into a large community including their families and friends, members of their church congregation, their neighborhood school, and an expanding circle of children who are her friends and companions..

Amber has had a powerful impact on the lives of many people; and the love and support of her family has been a moving witness in our community. Her mother says, "When we brought Amber home to be our daughter, we knew she needed us; what we didn't know, and what we keep discovering, was how much we needed her."

This book goes to the printers a few days after Mother's Day, 1992. As we were doing some final editing, Amber and her family paid a visit and shared the book that she had written during Young Authors ' Week at school - a Mother's Day present for her family. Amber has been using facilitated communication for about a month, and wrote and illustrated the book with the assistance of Carolyn Penner, her aide and friend. The words, and the selection of pictures, are Amber's. We reprint this work — a child's testimony to the gift of adoption — with the kind permission of the author.

THE CHOSEN GIRL

by AMBER Grade 5

DARLING
BABY GIRL
LONELY
BABY GIRL
WAITING
BABY GIRL



LOVING
FAMILY
LONELY
FAMILY
LOOKING
FAMILY



FINDING
BABY GIRL
CHOSING
BABY GIRL
NAMING
BABY GIRL, AMBER



HAPPY
FAMILY
HAPPY
AMBER
LOVING
EACH OTHER



JOEY...

BY MARCY SORICE

I watch him as he sits in his seat, the one he has created between the chairs of his parents. He started out on the other side of his mother, but has rejected that chair as not close enough.. His "chair" consists of a bit of his father's right leg and his mother's left.

I read about him this week. His parents are new to him, maybe a few weeks or months old. We are at a big meeting - the kind where many people stand about greeting each other and talking, before the presentations and speakers. Someone has given him an additional name tag beside his own with an arrow and the statement, "This is my Mom..." On any other child this would merely be cute, but on him it speaks volumes...

He looks to be about six or seven, and I wonder about his life before this moment. He is shy, looking at the floor with a little grin as you speak to him. He walks with the aid of crutches and looks through glasses which are much thicker than most. And I wonder if someone told his birth parents that he would never be "normal", whatever that is, and that the best place for him would be in an institution, away from harm, away from society, and therefore away from a loving family, friends, playgrounds, school, Nintendo...

My mind switches to the present as I see him reach up to touch his father's face, tracing his jaw with his small fingers. He then turns to nuzzle his mother's neck. These simple gestures bring tears to my eyes, as if every once in a while he has to reach out and touch them to reassure himself that they are real, maybe not quite yet trusting in the permanence of this love and security. I don't know his background - when he was abandoned, how deep his wounds, how long has he been aware of rejection, or how long before he will believe in this family with whom he has finally found the love and security of those who accept us for who we are and forever cheer us on.

*Every miracle
begins with the
simple act of
falling in love.*

- Morris West

I had been long aware of Project S.T.A.R. and the wonderful things they were doing. But here before me was a real little boy with stone-washed blue jeans and open-laced tennis shoes and a name tag that said, "This is my Mom..." A real little boy who now had a better chance to grow into a confident, loving man because he has been part of a real family; a family who like countless others, played, worked, went out to McDonald's and Chuckie Cheese's, disagreed and made up... loved.

6.

Education

INCLUSION VS EXCLUSION: SOCIETY IS AT A TURNING POINT

BY JACK PEARPOINT

"Those who are members of society, and those who are marginalized from society, have a great need for each other's gifts.

"The sand of ordinary life is lived in community where people spend their days doing very ordinary things. They write, talk on telephones, teach children, play with babies, wash dishes, go for walks, read books, and cry on each other's shoulders. All of this happens in ordinary places on commonplace streets, all the time, everywhere. This very commonness is a real gift, a real benefit not to be ignored.

The gift of surviving and growing through change belongs to the outcast.

Living on the margin either burns you out or kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and can just about taste it; someone who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions." (Judith Snow at Frontier college, October 1988, 89th Annual Meeting)

Our society has reached a turning point where we must make decisions about values, direction and budgets. We no longer have the luxury of buying a piece of all the solutions — and thus never having to answer hard questions. The hard questions are about values: what do we believe in? What kind of future do we want for our children? How do we get there?

My analysis identifies two opposing trends two waging factions — inclusion versus exclusion. This dilemma is broader than "schooling" and education. Most post industrialized societies have begun to come to terms with the fact of limited resources. The debate is between people who believe in exclusivity and those who believe in inclusion (egalitarian opportunity as the predominant value).

I believe that 'inclusive' options (all welcome) will utilize the talents of people who would be discarded and written off in the 'exclusive' model. The 'outsiders' will bring new perspectives and new talents to 'policy conundrums' where we are in a rut and need 'fresh ideas.'

The meaning of a policy of exclusion is revealed by a 'reliable' senior government official's retort when asked "What should we do about those who aren't in the 'main' stream?" He responded partly in jest, partly in frustration: "We train the best, and shoot the rest." The comment was off-hand but identifies the dilemma. The unstated underlying assumptions of exclusion are, among others, that:

- *We are not all equal in capacity or value.*
- *It is not feasible to give equal opportunity.*
- *We must choose and thus train an elite who will take care of the 'rest'.*
- *'They' will benefit through the trickle-down theory.*

Inclusion is the opposite and works from the opposite assumptions;

- *We are unique in value; however, each has unique capacity.*
- *All people can learn.*
- *All people have contributions to make.*
- *We have a responsibility and an opportunity to give every person the chance to make a contribution. The criterion for inclusion is breathing, not IQ, income, colour, race, sex, or language.*

Critics of inclusion say:

- *It's too expensive.*
- *'They' can't learn.*
- *'They' don't know what's best for 'them'.*
- *It can't be done.*

As a critic of exclusion, I say:

- *It's too expensive.*
- *'They' can learn.*
- *'They' - people - know a tremendous amount if asked.*
- *It can be done.*

It is unethical, politically unacceptable and repugnant to 'write off marginalized people in our society. The cost of 'welfare maintenance' is unbearable, either socially or economically. In short, exclusion does not work.

The critics are right if our thinking and answers are limited to the solutions we al-

ready have in place. I want to think about a new system, one that replaces the old, not just reforms it. My vision of the new system is based on the value that 'everyone belongs' - 'all welcome'.

We all have the power to listen to voices that are seldom heard. If we choose to make the time, to learn to listen, and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy, and find new hope in our future. There is power in the powerless. We can be catalysts, or encrusted residue. The choice is ours.

Faye and Amber (age 11) had finished dinner, and were watching the television news coverage about the April, 1992, referendum for constitutional reform in South Africa. Amber, who had been using facilitated communication for about a week, called out to her mother, and indicated that she wanted to say something.

Are you thinking about the vote in South Africa?

YES. Did you want to say something about

that?

YES BLACK PEOPLE AND WHITE PEOPLE DANCE TOGETHER. BEFORE BLACK PEOPLE MADE BE IN BACK. CEB... CEG... CEG (with increasing emphasis)

Celebrate, Separate?

NO.

(Later) Amber, were you trying to spell segregation?

YES!!

THE EMPEROR IS NAKED: THE MYTH OF SPECIAL EDUCATION

EXCERPTED FROM *IT'S ABOUT RELATIONSHIPS*, BY MARSHA FOREST

I think we've lost our hearts to a myth of special education. We've created a new breed of magician, witch-doctor, a teacher/car mechanic who we believe can "fix" children like we "fix" cars. But children aren't cars, they are flesh and blood. They bleed real blood and cry real tears when hurt.

I too came from this "magician" mode of thinking. I am a trained special educator. I taught in segregated schools and classes and I did the best I could at the time given what I then knew. But I changed!

I realized that the power of the segregated environment was teaching negative messages daily. The environment said, "You are not good enough to be part of the real school. You need special education" and this really means, "We don't want you with us." I realized that no matter how good a teacher was, I couldn't give my students what they needed most - real experiences and real relationships in a real school/ a real classroom.

I saw that the Emperor (special education) was naked (not working). I didn't

think I was bad or evil or horrible - I just saw that there was something better out there not only for my students but for me and my own family.

We need to shout this news from the rooftops: All children need to learn with and from other children. All children need to belong and feel wanted and loved. All children need to have fun and enjoy noise and laughter in their lives. All children need to take risks, and fall, and cry, and get hurt. All children need to be in real families and real schools and real neighborhoods.

A few days ago I was at a meeting enthusiastically telling stories of children I know who are fully included in regular schools and classrooms. A young teacher interrupted me.

"But what about getting Melanie to the bathroom?" she asked. "How can she go to the bathroom - she has no arms! It's just not practical."

I have always suspected that what drives most of special education is a preoccupation with bathrooms, toilet training and bowel movements. Now I was sure

this was true. "But what was really underlying this teacher's preoccupation with the bathroom?" I asked myself. My answer: FEAR.

The teacher was afraid of the unknown. She was afraid to admit her fear. She was afraid she might not know what to do with Melanie. She, as most of us, feared anything new and different. But instead of talking about FEAR she talked about the bathroom.

I wanted to scream at this teacher. "How can you be so ignorant - how can you be so cruel - how can you think of bathrooms when this kid needs friends, love, education. How can you be so out of it?"

Instead of screaming however, I took a deep breath and asked her what she wanted for her own son. I said, "God forbid your son was in a car accident today and he had to have a wheelchair to walk and a communication device to speak with you from today on. Where would you want him to go school when he gets out of the hospital? Where do you think he'd want to live and work and play?"

"Well, of course I'd want him to live at home and go back to his class," she answered without hesitation. "Oh, I see what you're getting at," she said with a wise smile.

I more calmly went on, "You see how we move to all the wrong issues out of our own ignorance, prejudice and fear and we lose sight of the real needs of children."

Let's look at some of the ridiculous things we do:

If a child needs more relationships - we give him less: we will assign an educational assistant and build a one-to-one dependency.

If a child needs more time - give her less hours at school and more hours riding around town to "segregation land" in a "special bus."

If a child needs normal behavior models - we give him six other kids, who scream, as his "pals" and then we wonder why he doesn't improve.

If a child needs more communication - we put her in a room with ten other kids who don't communicate well and again we wonder why she won't learn.

**THIS IS CRAZY-MAKING
BEHAVIOR
AND IT HAS TO STOP -
NOW!!**

Children don't need segregated community-based experiences in supermarkets.

They need to go shopping with their classmates when the need arises. Children at age ten don't need jobs outside of the school, they need to do errands in the school that are typical for ten year-olds. High school kids don't need work experience that's different than their typical peers. They need to build relationships so that their friends and the mothers and fathers of their friends who own stores or work in factories will encourage their co-workers to hire their son's friend. Most people get jobs through personal networks, not simply job experience programs.

Surely if we can put men and women on the moon, we can figure out how to get a five year old to the washroom and how to get a 21 year old a job! It is all pure nonsense that we can't do it. It is simply a matter of will.

**GRADE 7/8 AT ST.
FRANCIS SCHOOL:
MY GREAT TEACHERS
OF 1989!!**

Integration is happening. Several school systems in Canada and the United States are proving that true inclusion can work. These school boards are good places for ALL children. They have policies of equality on issues involving racial minorities, women, etc. They believe that EACH BELONGS.

Once one system can do it, it forces everyone else to prove why they can't. It is no longer up to us to show why integration can work. We know it can. It is up to others to show why they can't do it.

We know the blocks aren't money or staff. We know it is strong leadership and clear values that make the difference. We need to applaud those who believe in love and inclusion and expose those who would create a new elite in our schools.

When the staff decided to welcome all children back into regular classes at St. Francis Elementary School (Waterloo Region Separate School Board) we simply went to talk to the children and ask them what they thought about this issue.

Their questions and responses touched everyone involved. (The reader can watch and hear these children in the video With A Little Help From My Friends.) Some of their questions were:

"Why did we segregate May in the first place?"

"What was Jason learning in the "life-skills" room anyway - nothing I think."

"How would you feel if you weren't with kids your own age and had to go on "special" trips to the circus, bowling and that stuff."

We had to answer these and other questions. Entering into honest dialogue with

children wasn't always as easy for the teachers. "I know how to teach these kids, but I've forgotten how to talk to them," one teacher admitted.

We ask the children how they would feel if they had no friends, if no one ever called them, and if they never could go to parties, sports events, etc. with their friends. We explained that most people with disabilities had few people in their lives other than those paid to be in their lives. How would that make you feel?

"I'd feel old."

"I'd want to die."

"I'd feel like I was in jail."

"I'd think only the teachers were my friends."

"I'd commit suicide."

And so all the children previously in segregated classes were "welcomed home."

Everyone was nervous, no one knew what individual programs would look like, but with team work and support everyone survived and indeed thrived. Today the Waterloo Region of the Separate School Board is a model. People flock to Kitchener from all over the world to see inclusion in process.

If you visit you won't see the perfect school or system. It is far from perfect but it is on the road. It is, after all, just a school system and has

It is impossible to train people in the abstract to do this kind of work. There is no way to do in-service for this NEW WAY OF THINKING EXCEPT to have the children present and discuss values and attitudes, cry and laugh together and work cooperatively as problems arise. It is no longer the lone ranger teacher having to come up with the answer. It is the whole school and community, parents, consultants, and most of all, the children who can help.

It may be, then, that form serves us best when it works as an obstruction to baffle us and deflect our intended course. It may be that when we no longer what to do we have come to our real work, and that when we no longer know which way to go that we have begun our real journey. The mind that is not baffled is not employed. The impeded stream is the one that sings.

*- Wendell Berry,
Standing by Words*

Every Mohawk is a Horseback Rider

- BY JACK YATES

Several years ago I had the opportunity to visit a summer day camp near Albany, New York. It was a typical day camp in many ways. About three hundred campers came each day, and they were organized by age groups. So the ten year-old boys were the Tigers, the eight year-old boys were the Eagles, the nine year-old girls were the Apaches, and the twelve year-old girls were the Mohawks. Through the day, campers in their groups engaged in activities typical of a day camp: swimming, canoeing, nature groups, horseback riding, and so on.

One thing was not so typical at the camp, however. Its owner and director, Ben Becker, decided that it would be a good learning context for everyone concerned to

have a number of campers who were children with physical and mental handicaps. So he had an informal quota system to ensure that five or ten percent of the campers in any given week were children with handicaps, and he gave out scholarships to assist in this plan. Thus when the Mohawks went horseback riding, not every Mohawk could just jump on a horse and ride; and not every Mohawk could learn as easily or as quickly as every other Mohawk.

riding with the Mohawks, another girl would ride along-side for encouragement, and sometimes on curves one of the counselors would run along the other side of the horse, like a spotter in gymnastics. We certainly don't want Mohawks falling off horses. Another of the Mohawks was a girl who had polio as an infant, and she had no control at all over her legs. So when she went horseback riding with the Mohawks, one of the bigger girls who was already a good



For instance, in the group of thirty Mohawks, one was a girl who was blind. So when she went horseback riding with the Mohawks, another girl rode on another horse next to her, to call over instructions and encouragement. Another of the Mohawks was a girl with cerebral palsy, and she had limited control especially on one side of her body. So when she went horseback

rider would ride in back of her saddle, holding her shoulders to make sure she would stay on the horse.

We visitors on a PASS team were very impressed with Ben Becker's camp, but it was only looking back a few years later that I realized that his camp operated under a rule, that every Mohawk is a horseback rider. They didn't state it as a rule, but that was the principle which

guided the camp every day.

In human services for people with handicaps, back in the bad old days, we seemed to operate under a different rule, essentially that some people are horseback riders and some aren't. It's a shame, really, since horseback riding is such a fine experience, but some people just don't have it in them to be horseback riders. Now in services in these more progressive days, it seems that we most often operate under a more enlightened rule. We have expectations for all of our campers, so our rule now is that every Mohawk will be a horseback rider, someday. In the meantime, we'll hire the best teachers and gentlest horses for our special group of future horseback riders, working with them patiently and intensively until, someday, I know it will come, they will be able to become horseback riders and rejoin the Mohawks.

Doesn't sound so bad. But at Ben Becker's camp they had a different rule: every Mohawk is a horseback rider, now, today. What varies is not who is a horseback rider and who is not; every Mohawk is a horseback rider. And what varies is not when someone will attain horseback riderhood; every Mohawk is a horseback rider. What varies is only how much help a person needs to stay in the saddle.

EVERYONE BELONGS: BUILDING THE VISION WITH MAPS - THE MCGILL ACTION PLANNING SYSTEM

BY MARSHA FOREST AND JACK PEARPOINT CENTRE FOR
INTEGRATED EDUCATION AND COMMUNITY - TORONTO

A shared vision has caught the imagination of parents and educators across Canada: a vision of all children - including those with severe disabilities - being educated in regular classrooms is founded on a simple, yet profound philosophy: Everyone belongs. MAPS, the McGill Action Planning System, is a systems approach to problem solving that has helped many schools turn vision into reality. MAPS was designed by a team of educators who were searching for ways to help welcome children with disabilities back into regular schools and classrooms. The original MAPS team consisted of the two authors, plus Judith Snow, Evelyn Lusthaus, and John O'Brien.

Assumptions of the MAPS Process

1. All people are valuable and can contribute to life on this globe.
2. All people have abilities, talents, and gifts.
3. All people can learn.
4. Disability is a social construct. People are not disabled; systems disable people.
5. There is a real need for support, services, and educators who will reach out and nurture the potential of every child.
6. The only label we recommend is a person's name. Labels hide the fact that we really don't know what to do. After that, we suggest adopting a problem-solving mode that creatively figures out what to do for each unique individual.
7. Common sense is the most important and least common sense.

Who goes to a MAP? - Friends!

The size of the group that gathers for a MAP session can vary from two to two dozen. The key ingredients for participants are Intimate and Personal Contact with the individual being mapped. A grandmother or neighbor, a friend -

all are on equal footing with professionals, who are welcome and needed but as individuals -not as "therapists". Parents and family members usually have the most to offer, if asked. Their perspectives are all welcome in a MAP.

Peer participation is critical. Class/age-mates have enormous untapped energy and creative capacity. Their "straight talk" often empowers teachers with new ideas. Adults must be careful not to constrain or downgrade the participation of peers: They are critical and equal partners in the MAPS process.

There is a delicate question about whether or not the individual who is being "mapped" should be present. It is a judgment call; it works both ways. We hedge toward full participation. People understand an enormous amount - more than we think. Also, a MAP is an "upper," a real boost for an individual who previously has been excluded. Full participation also saves time in trying to explain it all later.

What Happens at a MAP? How Does it Work?

"Mapping" is a collaborative problem-solving process aided by a two-person team of Facilitator and Recorder. The Facilitator, positioned at the open end of a half circle formed by the participants, presents eight key questions to the group. The Facilitator must be skilled in group process and have a problem-solving orientation. Most important, the Facilitator must be committed to building an integrated school community. The information and ideas generated during the session are marked on a large piece of chart paper by the Recorder. Public charting is vital to the MAPS Process: It generates "images" that help participants visualize the relationships between and among people and actions, thus promoting the creation of additional problem-solving strategies, and it serves as a permanent record of the plans and commit-

ments made by the group. The Recorder need not be an artist, but it is vital that the MAP be printed or written clearly, using the participants' words. The chart should include contributions from everyone in the group.

MAPS planning typically occurs in one or two sessions, and approximately 3 hours are required to fully address these questions.

1. The Facilitator begins the MAPS process by asking participants, "What is a map?"

A recent group gave these answers:

Something that gives direction

A thing that helps you get somewhere

Routes to different places

A way to find a new way

Stops you from getting lost

2. What is the person's history? The participants most intimate with the child being mapped, usually parents and family members, are asked to give a short, 10-15 minute history focusing on key milestones and events in the individual's life.

3. What is your dream for the individual? This question is intended to get people, especially parents, to imagine their vision for the child's future. Many parents of children with handicaps have lost their ability to dream about what they really want for their child rather than what they think they can get. The vision of the future should not be limited by money or current realities. This question helps the group focus on the direction in which the individual is now heading and encourages concrete action plans for realizing the vision.

4. What is your nightmare? This question is the hardest to ask, but very important to get on the table. We must understand the nightmare in order to prevent it. No parent has ever said, "I'm worried that my child won't attend university, won't get an A on the next test, or won't learn to spell." Instead, the

nightmare question brings out what is in the heart of virtually every parent of a child with a severe handicap: "We're afraid our child will end up in an institution, work in a sheltered workshop, and have no one to care for her when we die." The MAPS planning must reflect an understanding of the nightmare; preventing the nightmare is one measure of its success.

5. Who is the individual? With this question, the MAPS process shifts into a no-holds-barred brainstorming mode. Participants are asked to give words or phrases that describe the person being mapped. The rule is: no jargon, no labels; just describe how you see the person. The image of a unique and distinct personality should emerge. Here are example from a recent MAP for Miller, a 14-year-old who, to some, is "severely handicapped and mentally retarded."

She has a brother
She gets around in a wheelchair
She's lots of fun
She's active like crazy
She's radical/bad (really means good)
She's temperamental
She likes to touch
She wants to be involved
She looks at you
She can talk some

6. What are the individual's strengths, abilities, gifts, and talents? All too well we focus on the things a child with a disability can't do. It's vital to build upon strengths and abilities. This can be a difficult question for parents, who have been struggling with negatives for so long. This question is also intended to produce a brainstormed list from the entire group. Here's part of the list generated for Miller:

She can make us laugh
She moves her arms, can throw a ball
She likes to listen to music
She's persistent, tries real hard

She can count and remember numbers
She enjoys stories and movies

7. What are the individual's needs? This too is a brainstorm. Don't let people stop each other, but don't get bogged down either. Keep it short and record people's words and perceptions. Parents, teachers, and peers often have different perceptions about needs. For Miller, it was decided that what she needed most of all was:

A communication system that lets her express her wants and feelings
More independence with dressing and other self-care skills
To be with her own age group
Places to go and things to do after school
Teenage clothes

8. What is the plan of ACTION? This is the final, and most important question of all. The MAPS planning group imagines what the individual's ideal day at school would look like and what must be done to make it a reality. Step by step, the MAPS group goes through an entire day, envisioning the various environments and activities the individual will experience and what kinds of resources, supports, and adaptations can be created to make the day successful. For example, a peer volunteers to meet the taxi that brings Miller to school each morning and walk with her to the classroom; during language arts period a classmate will help Miller practice with her communication board; and the principle of partial participation will be used on the playground when Miller bats in the softball game and a teammate runs the bases for her.

In addition to describing what a MAP is, we believe it's important to emphasize what MAPS is not:

1. A MAP is not a trick, a gimmick, or a quick-fix solution to complex human problems, MAPS is not a one-shot session that

scope as the outcome of each MAP. It is a medley of people working together to make something unique and better happen. It is more than anyone can do alone.

For additional information and training materials on MAPS, write the Centre for Integrated Education and Community, 24 Thome Crescent, Toronto, Ontario, Canada, M6H 2S5.

To speak and not punish. To speak and not condemn. To speak in order to educate and enrich, not to repudiate and humiliate. To speak and to cure, not to hurt and wound: Rebbe Wolf of Zbarazh believed in using language exclusively on behalf of man, never as a weapon against him.

*- Elie Wiesel,
Somewhere a Master*

No Magic Bullets No Micro-Wave Solution Just Hard Work

We make no claim that a MAP or a CIRCLE as described in this article is a magic bullet or microwave solution. These strategies, developed and practiced for a decade with live children in real school systems in Canada and the USA, are simply tools in the arsenal for quality education for all - a dream we believe to be viable and necessary.

The MAPS strategy has been pioneered and used by many teachers and families in the past ten years. The laboratory has been school boards in Canada (the Hamilton-

Wentworth Separate School Board under the leadership of Jim Hansen, and the Waterloo Region Separate School Board under the Directorship of George Flynn). First and foremost, these two boards (approximately 20,000 students each) believe wholeheartedly that:

- all students belong in regular class rooms - no ifs, ands or buts
- ordinary teachers can teach all children
- necessary supports will be provided when necessary
- quality education is a right not a privilege
- outcomes must be success, literacy and graduation for all
- creative alternatives will be available for populations not succeeding in the ordinary fashion (i.e., they developed storefront schools, cross-age tutoring, alternative high school programming as required).

A Cookbook Lesson

We love to eat and cook. A quote from the back cover of the original 1973 version of Tassajara Cooking sums up our feelings about the strategies we have developed:

"This is a book to help you actually cook - a cooking book. The recipes are not for you to follow, they are for you to create, invent, test. It explains things you need to know, and things to watch out for. There are plenty of things left for you to discover, learn, stumble upon. Blessings. You're on your own. Together with everything."

We invite you to treat MAPS and CIRCLES as recipes from "Tassajara Inclusion Cookbook", MAPS & CIRCLES are designed to help you do it... not to do it for you. You must "create, invent, test. They explain things you need to know, and things to watch out for. There are plenty of things left for you to discover, learn, stumble upon. Blessings. You're on your own. Together with everything."

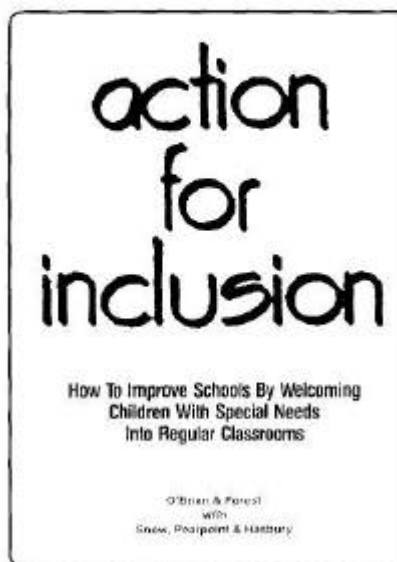
We recently received a phone call that illustrates the dangers of seeing strategies as "magic bullets." The organizer of an upcoming workshop called and asked, "Will the participants at your workshop really leave knowing how to include all kids in regular classes?"

Marsha took a deep breath and answered in a friendly but firm tone, "No. In two days you don't learn brain surgery and in two days no one person can learn "IT" i.e. how to integrate all children magically into school. We hope the participants will get a tasty appetizer which will give them the inspiration and confidence to begin, and to continue to get more in-depth knowledge, training and experience of the issue." The caller reframed the concern, and inquired if a reasonable revised objective might be that everyone leave the workshop feeling confident for their school system. We said that was our hope, and that most people would be ready to dive right in and try it out!

It is glib to think that anyone will learn all they need to know about dealing with children with complex needs in two days. But, with consistent use of MAPS and CIRCLES strategies, as well as other exciting state of the art approaches, within a year, we have found great success in being able to include almost all children.

What we've learned in ten years is that we can welcome ALL students into our nation's schools and classrooms - if we want to. This is regardless of the complexity of children's needs - be they physical, mental or emotional. After all, "untrained" parents have been doing it for years. As one of our friends said after the birth of her daughter - "Jane didn't come with a set of directions. If we figured it out, so can a school. After all, teachers are trained educators, and we're not!! It should be easier for them. Basically, it is very simple. If they want Jane, they'll figure out just like we did. All it takes is time and love."

ACTION FOR INCLUSION



Inclusion Press

Action for Inclusion: How to Improve Schools by Welcoming Children with Special Needs into Regular Classrooms, John O'Brien & Marsha Forest, with Judith Snow, Jack Pearpoint & David Hasbury; 1989; 53 pp.; **\$12.00 CDN** from: Centre for Integrated Education and Community, 24 Thome Crescent, Toronto, Ontario M6H 2S5. **\$10.00** (plus \$0.50 shipping) from: Expectations Unlimited, P.O. Box 655, Niwot, Colorado, phone (303) 652-2727.

This is an extraordinary plain language guide to inclusion. Nominally it is about education, globally it is a guide to building inclusive communities of living. It's not a tool — it's a way.

JOHN MCKNIGHT
NORTHWESTERN UNIVERSITY

People call me every day asking for assistance in including children with challenges into regular schools and classrooms. I can think of no better resource or information than this book. Finally, I can give people information that is clear, concise, and represents years of experience and thought.

JAN NESBIT, PH.D., DIRECTOR,
INSTITUTE ON DISABILITY,
UNIVERSITY OF NEW HAMPSHIRE

Action for Inclusion provides the clearest "pattern" of values, ideas and action steps that we have ever seen for parents, teachers, administrators, and integration facilitators. It generates understanding and mutual respect, and ought to be in the hands of every parent of a child who has a child with a disability.

- DAVID WETHEROW

SEEING THE WHOLE PROCESS.

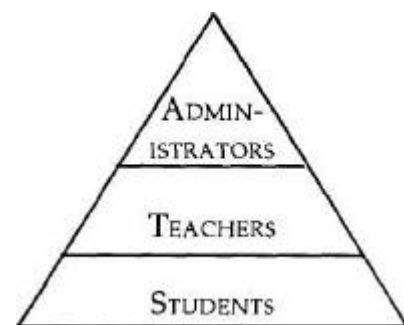
HERE IS ONE WAY TO VISUALIZE ACTION FOR INCLUSION. AT THE BEGINNING, THINGS OFTEN LOOK LIKE THIS:

The only label we need is the child's name.
- Marsha Forest

RESOURCES
DIVIDED



NEIGHBORHOOD SCHOOL



Inclusion begins in the love of parent for child. Parental love forms the foundation for acceptance of the child's unique value as a person. Recognition of the child as a person first, beyond any labels or categories, grows into the desire for the child to be a valued participant in ordinary life. Parents are the first people able to name their child's gifts and the first people able to dream of inclusion for their child.

Social expressions of prejudice threaten the dream of a child belonging to family, school and community.... [but] despite the nightmare, the dream survives. Because of the nightmare, the dream may be a closer kept secret... sometimes we meet families in which husband and wife

have not spoken their dream aloud to one another.... The answer to unacceptability and rejection can't be found by keeping people with disabilities away from other people. The answer is to create places that welcome all people regardless of disability and offer each person the chance to belong and contribute. In such places, people with disabilities find the security of membership and friendship... The answer is to create places in which each person is part of a circle of friends who support one another, challenge one another, and stand up for each other. The nightmare reminds us to be careful, to look out for problems and dangers, and to anticipate much hard work to overcome social prejudice. The answer lies in pursuing the dream into action.

Enlist the principal...

The road to inclusion leads directly to the neighborhood school principal's office door.... Denial of permission by the principal makes inclusion impossible; permission defines the minimum for an inclusive classroom. When a principal actively leads a school in a focused effort to improve quality, things will get better for teachers, students, and parents concerned with education. The principal's active support makes an inclusive school possible....

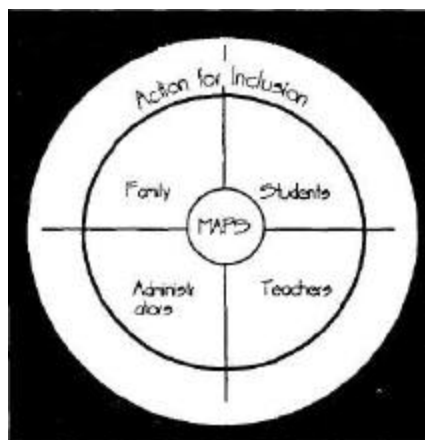
This phase of *action for inclusion* aims to get the neighborhood school principal to consent to the inclusion of the excluded student in a regular classroom, with necessary supports, and to select good teachers to include the student.

Do your homework. Careful planning of the first approach to the principal pays off. Find out about the school, the principal and the school system. Are there other inclusion efforts in the school or in the district? What has happened with them? What is the attitude of the school board toward inclusion? What efforts to improve quality involve the principal now and how can you link your request for inclusion to them? What is the principal's style of decision-making?

SEEING THE WHOLE PROCESS...

ACTION FOR INCLUSION
BUILDS AND MAINTAINS [A] CIRCLE
FROM RESOURCES THAT ARE
TYPICALLY FRAGMENTED.

RESOURCES
ALIGNED



EXTRAORDINARY BECOMES ORDINARY IN TWO CONNECTICUT SCHOOLS

- GEORGE DUCHARME
AND PAT BEEMAN

Monday morning in second grade - the crew files in. Some wash sticky hands and hang jackets in preparation for the day. Others stow clanging lunch boxes and backpacks stuffed with the essentials (after-school clothes, favorite toys, show-and-tell gear - the usual). Morning rituals follow: the livelier crowd around teacher Janet Haines sharing tales of weekend adventures; the bleary-eyed shuffle to their desks, quietly contemplating the day.

Matthew removes his sweater, scoops up a favorite book from the shelves and sits at his desk. Like many of his peers, Matthew is an avid reader bursting with curiosity. According to his mother, Norma LoMonaco, Matthew "enjoys complex things and has a great ability to question" even if he doesn't always understand the answers. In nearby Mansfield,

Connecticut, Matthew's friend Pete Bradeen, another avid book lover, is also entering his second grade classroom.

At first glance Matthew and Pete don't seem unusual placements in their classrooms. Yet without persistence from their parents and cooperation from exceptional teams of teachers and resource staff at Windham Center and Annie E. Vinton schools, both boys would have been in special education classrooms or schools out of their neighborhoods. Matthew and Pete both have Down's Syndrome, and both are in their second year of integrated experience.

The LoMonacos and Bradeens decided early on that their children's futures would not be limited to the emotional and physical walls of institutional life. "You have to decide what you want your child's life to be like," says Mary Bradeen, Pete's mother. As a result, Matthew and Pete are attending school with potential employers, employees, and friends. Suddenly, LoMonaco, small in her overstuffed chair, leans forward and says with intensity, "You can't imagine how I felt when I saw Matthew beaming when I dropped him off at a birthday party. Kids were greeting him with

such familiarity." Mary Bradeen nods her agreement and emphatically adds that if Pete and Matthew weren't attending neighborhood schools, they would be isolated from the same children with whom they attend church and share neighborhoods. Without the constant interaction that takes place in schools, meaningful friendships are difficult to develop.

Friendships don't seem to be a problem for these boys. On a muggy Sunday afternoon teeming with mosquitoes, I met both families at the LoMonacos' home. Suddenly out of nowhere, five children appeared to recount the day's swimming pool adventures, tales of family pets, and riding the bus together. The boys' language is sometimes difficult to understand, so when Pete proceeded to excitedly explain about the family dog gathering frogs from the backyard with her mouth, two of the LoMonacos' children, Sarah and Bethany, eagerly translated (magically and delicately, without interrupting conversation flow!). Eventually, I grasped the art of listening, and then explained to Pete, an eager listener, my own dogs' penchants for frogs and cats.

While the children played outside or in the next room, occasionally popping

in for a hug, the parents explain another reason for integration. By building bridges between community and their children, both the boys and their peers are learning new concepts for understanding and coping in a world brimming with differences. The boys seem to have similar networks of friends at school. A child in Matthew's "circle of friends" routinely helps Matthew negotiate second grade rituals. With this responsibility for helping Matthew has come more self-esteem, maturity, and a new ability to focus on work.

Though having Matthew and Pete integrated is challenging for teachers and classroom aides, the addition of academically challenged students provides opportunities for life lessons on differences. For example, one day last year, according to Deb Sundin, Pete's first grade teacher, some children asked why Pete wore glasses. This question provided an opportunity for children to discover that many of them had other distinctive physical characteristics, including hearing aids, brown eyes, blue eyes, tall, or short, making them different from their peers. Even stories about physical differences such as "Otto the Octopus" or about welcoming newcomers who might be different from

others like "Our Veronica Goes to Petunia's Farm", take on new meaning when the children experience firsthand the need to understand.

Matthew and Pete's classroom work is modified, allowing them to stay in regular classrooms. LoMonaco says, "Matthew is experiencing significantly more academic success in his integrated classroom than in his previous special education placement." Though the future is uncertain, at Annie E. Vinton and Windham Center kids say, "Pete's the guy in my class" or "Matthew is a great bike rider" instead of "there go the kids in the special class down the hall." And, when Pete and Matthew go home, friends call them on the phone or come over to play.

While integration is gaining nationwide attention and acceptance it continues to be a topic saturated with politics, the realities of budget constraints, and pedagogical differences. Last year Mary Bradeen and Norma LoMonaco spent almost 30 hours per week advocating for their children and other children, negotiating school system bureaucracy and finally securing the right for their children to attend schools - and meet good friends.

MILLER'S MAP

Miller's Map is a 40-minute gem! This excellent teaching tool shows the MAPS process in action and illustrates how full inclusion can work for Miller Cairns or any other child in the world. It shows how to make inclusion happen by involving children, parents, neighbors, and professionals in a creative team process. The use of color graphics and the detailed daily plan to make Miller's ideal day a reality is practical and useful.

The classmates and family give moving testimony that Miller belongs with them and should not ride alone on a bus to a special class as she did when she first attended school. A practical tool for teachers and parents.

RAY MURRAY
DIRECTOR, SCHOOL OF
SPECIAL EDUCATION
AUCKLAND COLLEGE OF
EDUCATION, NEW ZEALAND

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652-3737 FAX

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Toronto, Ontario
CANADA M6H2S5
(416) 658-5363 Phone/FAX

Nurtured by Love, Shinichi Suzuki, translated by Waitraud Suzuki; 1983; 108 pp.; from: Senzay Publications, Ability Development, Athens, Ohio

I came across this book totally unsuspecting. One day, my husband came home and announced that he had bought a piano and had enrolled our two children in piano lessons. These were no ordinary lessons. They would begin in the "Suzuki method to piano". I had never heard of such a thing and I suppose I protested so much that within a few days, my husband presented me with a copy of *Nurtured by Love*. You must be wondering what does a child's piano lessons have to do with a whole community. Bear with me.

Shinichi Suzuki was born in Japan, a son of the founder of the largest violin factory in the world and a talented violinist himself. Suzuki was also a violin teacher for one asked him to teach his son the violin. We were at a loss as to how to teach such a young child. This event led way to the conceptual development and practice of what Suzuki calls, "Talent Education":

For thirty years now I have been pleading with people to believe that all children can be well educated, and not to turn away those who drop behind in learning. I named my method Talent Education, and began an educational movement in which children dropping behind or struggling to get along are not turned away. The day of my startling discovery became for me the starting point in my search for human potentials. And how did I fare? With glances back at the past and full hope for the future. I should like to tell the story.

From Suzuki's book and also from my own experience, I can explain to you the essence of the Suzuki method. Talent Education is a process by which no child is turned away. There are no try-outs to see who is "better" than another. Children are not grouped by their expertise in music. All children learn together. All children are valued for their hard work and individual accomplishments no matter how small. I will never forget the first time my

children were scheduled to "perform" in a Suzuki concert. The first performance for all beginning Suzuki students consists of walking to the stage, turning to face the audience, putting on a big smile, and taking a bow. That's it. At first I thought this really strange. My feelings changed when my children one by one went to the stage, smiled nervously and bowed and the whole audience of other parents and families erupted in an immense applause. You would have thought that they just played a Beethoven sonata. My children left that day feeling valued and proud of their "performance." Soon, I became immersed in the Suzuki culture where no child is competing against or being compared to another. Do you know how foreign this concept is in our culture? Suzuki method for me has taught a lot about community. Imagine, no one cares what you can't do. You are valued for your ability. After reading *Nurtured by Love*, I realized that Suzuki never believed that he was going to be turning out hundreds and hundreds of world class musicians (although he has). He explains his method is to turn out children with fine character and noble spirit and to do that through music. He writes:

I feel respect and friendly feelings for everyone. In particular I cannot help but feel respect and warm friendship for small children. And my heart brims over with a desire to help make all children born upon this earth fine human beings, happy people, people of superior ability. My whole life and energies are devoted to this end. This is because of my discovery that every single child without exception, is born with this possibility... People today are like gardeners who look sadly at ruined saplings and shake their heads, saying the seeds must have been bad to start with, not realizing that the seed was all right, but that their method of cultivation was wrong. They go on in their mistaken way, ruining plant after plant. It is imperative that the human race escape from this vicious circle.

Isn't a whole community about just this - finding a new way of cultivation the spirit?

- SHARON GRETZ

7.

Housing

In "The Grass Roots Housing Process", the California architect, Christopher Alexander, makes it clear that what we usually think of as "the housing problem" is actually *a finance* problem. In his discussion, Alexander focuses on the cost of borrowing, which, for most of us, eats up two out of every three housing dollars (this is true whether we own or rent - we're still paying off a mortgage). He points out that this problem cannot be solved "by making more houses which are commodities; nor by making better houses which are commodities; nor by making cheaper houses which are commodities. It can only be [solved] when we stop treating houses as commodities altogether..." Alexander goes on to propose a building/financing process which involves the development of a house over *time* -- building without borrowing, building slowly and incrementally, rather than struggling to capitalize a house which someone else has built.

None of the public housing, or subsidized housing, programs operated by state/provincial and federal agencies do anything to address this problem ~ they *shift* the burden of the mortgage problem, but they have not *solved* the problem. In many cases, they create new problems, by segregating and congregating poor people in public housing projects. The result is not "low-cost" housing, in any sense of the word.

The second finance problem is simply the lack of personal income that defines the lives of so many people with disabilities. People do not have enough money to live decently, and we try to solve the attendant problems by creating *programs* (for housing, transportation, food, etc.). Each of these programs competes with all other programs for financing and public support; each carries an administrative burden; all have waiting lists; none do the job. How much simpler it would be to provide income!

However, we're not there yet, and meanwhile, there are a handful of developments that make sense from the standpoints of financing and community-building. The three that we're aware of (there are probably more — let us know for future editions) are the concepts of cooperative housing, "co-housing", and Habitat for Humanity. Each has a different approach to the question of financing; each directly addresses the question of how to build communities that work; and each has, we believe, considerable potential for the inclusion of people with disabilities. It makes a big difference when people are living in a context that has a focus beyond "taking care of people with disabilities". Habitat, cooperative housing, and co-housing all provide public contexts in which peoples' gifts can be expressed, valued and celebrated.

COHOUSING



Cohousing: A Contemporary Approach to Housing Ourselves; Kathryn McCamant and Charles Durrett; 1988; 208 pp.; **\$28.00** from: Habitat Press, 48 Shattuck Square, Suite 15, Berkeley, California 94704

"I know I live in a community because on a Friday night it takes me 45 minutes and two beers to get from the parking lot to my front door."

- Trudeslund resident

This book comes like a breath of fresh air. The authors look insightfully at places where people have chosen to provide for community as well as privacy... A fascinating account about a topic presently of small dimensions, but of enormous importance for the future of housing, and of us all.

- CHARLES W. MOORE, ARCHITECT

When we think about the kinds of arrangements which could provide sustained, practical support to families of children and young adults with disabilities, we are struck again with the impracticality of the isolated-nuclear-family, detached-housing, bedroom-community housing style that defines most of our lives. Our friends who have children with disabilities have to make elaborate arrangements to bring their kids into connection with friends, neighbors, and extended family members. In the Northern prairies, Winter turns even the simplest neighborly visit into a full-scale production involving endless layers of clothing, unreliable wheelchair transportation, icy porch steps and kids frozen like Popsicles. We've thought a lot about creating small clusters of housing which could make easy connections with neighbors a natural daily occurrence. Readers of Cohousing may not go out and develop the kinds of projects described in the book, but many of the ideas and

visions can be put into practice in ordinary neighborhoods. Anyone designing housing cooperatives or thinking about moving closer to supportive friends and family members will profit from this beautifully illustrated book.

This book is about places which expand the meanings of "neighborhood," and "community." We wrote it to share the inspiration found in these places with others who have also dreamed of a home that not only provides shelter, but is also part of a community. We hope that the book will inspire people to take a more active role in creating the home and neighborhood they want to live in.

In Denmark, people frustrated by the available housing options have developed a new housing type that redefines the concept of neighborhood to fit contemporary life-styles. Tired of the isolation and impracticalities of single-family houses and apartments units, they have built housing that combines the autonomy of private dwellings with the advantages of community living. Each household has a private residence, but also shares extensive common facilities with the larger group, such as a kitchen and dining hall, children's play-

rooms, workshops, guest rooms, and laundry facilities. Although individual dwellings are designed to be self-sufficient and each has its own kitchen, the common facilities, and particularly common dinners, are an important aspect of community life both for social and practical reasons.

Advantages for Children

With nearly fifty children living in Trudeslund, there is no lack of playmates. The pedestrian-oriented site gives them lots of room to run without worrying about cars. The community serves as a large, extended family—children have many people besides their parents to look after them, to whom they can turn for assistance, or just talk to. It becomes second nature for the older kids to keep an eye on the smaller ones, and the adults know every child by name.

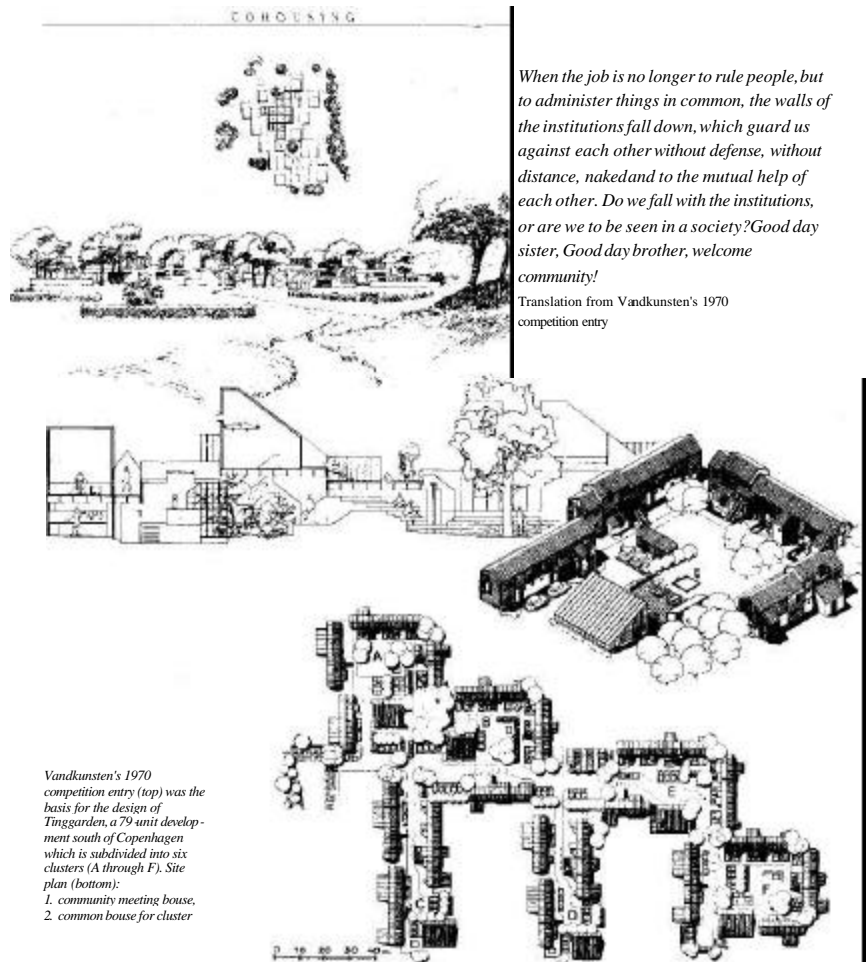
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An Old Idea — A Contemporary Approach

In many respects, cohousing is not a new concept. In the past, most people lived in villages or tightly knit urban neighborhoods. Even today, people in less industrialized regions typically living in small communities linked by multiple interdependencies. Members

of such communities know each other over many years; they are familiar with each other's families and histories, talents and weaknesses. This kind of relationship demands accountability, but in return provides a sense of belonging.

primarily residential, daily patterns develop that begin to weave work and home life together again. Most cohousing residents go outside the community for their professional work, but there is also informal trading of



Vandkunsten's 1970 competition entry (top) was the basis for the design of Tinggarden, a 79-unit development south of Copenhagen which is subdivided into six clusters (A through F). Site plan (bottom):
1. community meeting house,
2. common house for cluster

When the job is no longer to rule people, but to administer things in common, the walls of the institutions fall down, which guard us against each other without defense, without distance, naked and to the mutual help of each other. Do we fall with the institutions, or are we to be seen in a society? Good day sister, Good day brother, welcome community!

Translation from Vandkunsten's 1970 competition entry

?

In preindustrial communities, work is integrated with the rest of life. Small towns are not divided into residential, commercial and industrial areas; rather, residences are built on top of shops, and cottage industries flourish throughout neighborhoods. Although cohousing developments are

skills within the community. One resident, a doctor, tends the cuts of a child who has fallen. Another helps repair a neighbor's car. Several residents make wine together. These neighbors know each other's skills and feel comfortable asking for assistance, understanding they will be able to reciprocate later.

COOPERATIVE HOUSING

Cooperative ownership of housing makes it possible for people who would not ordinarily be able to own their own homes to share the benefits and responsibilities of ownership. It also offers people an opportunity to create neighborhoods of mutual support, and possibly to become eligible for public assistance in financing their homes.

All cooperatives (housing, employment, and consumer co-ops) are based on a simple set of principles: ownership and control by the members, democratic control (one member, one vote), limited equity (individual members cannot take control by purchasing more shares), and limited liability. In addition, cooperative *traditions* encourage mutual assistance, support to the larger cooperative movement, and continuing education and skill development.

Cooperative housing can help overcome the lack of empowerment which is observed in most "residential services" for people with disabilities. In the typical residential service (especially group residences), the people served have no security of tenure, i.e., none of the privileges or responsibilities of home ownership, or even the limited protections of commercial tenancy. Typically, the organization that runs the service also owns the build-

ing, so anyone who comes into conflict with the service provider is also in jeopardy of losing his place in the community.

[This observation is the basis for what we believe is a good principle in the development of residential supports in general: it is a good idea to separate the administration of support services from the ownership of housing. Then, if someone comes into conflict with the service provider, he doesn't lose his house, and he may be able to negotiate for support services with another provider. Also, someone can change houses and continue to receive support from a provider in whom he has confidence.]

Another pattern in many residential services (including many "supported apartment living" arrangements) is that many people continue to live in isolation from the surrounding community. My office is in an apartment building (about 100 units) where ten people with physical disabilities live in their own apartments and share an attendant care system. We couldn't live in closer proximity if we tried! But there is virtually no interaction between these ten young people and the other tenants in the building. Independent - but isolated. Why is that?

The fact is that there is no "community" in that building, even for the ninety-

plus people *without* disabilities. There is nothing about the way the building is organized that brings us together. Since we have no work to do together, ordinary shyness, plus the fear that people experience in connection with disability, keeps us strangers to each other.

Cooperative housing can be a way of breaking through all of these barriers at once. It has the potential to provide security of tenure, to help sort out the confusion between services and housing, and to involve disabled and non-disabled members in a mutual effort that creates the potential for friendship.

How does a housing cooperative work?

The people who will develop the housing project form a special type of corporation (the "cooperative").

Each member owns one share in the co-op (usually costing a nominal amount), and has one vote in general

membership meetings.

The members elect a Board of Directors from among themselves. The board is always accountable to the general membership.

The board *may* hire a property manager, or it may contract for these services, or the members manage the property themselves on a volunteer basis. In all cases, the management is ultimately accountable to the general membership.

The cooperative (as a corporation) develops or purchases housing, often with financial assistance or low-cost loans from government. Non-profit housing cooperatives are often eligible for public assistance with financing under municipal, state, provincial, or federal housing programs.

Members occupy individual units of housing based on an occupancy agreement. Members do not "own" their individual units - rather, they own a share in the cooperative, and the sell the share

back to the cooperative when they move out.

Community-building in a housing cooperative.

Development of a housing cooperative provides an important opportunity for members and potential members to get to know each other intimately, to work collaboratively on a complex project, to gain an understanding of each others' strengths and gifts, and to decide what kind of a community they want to create and work for.

One of the continuing lessons for members in all kinds of cooperatives is that there is no "them". Ultimately, all action, or inaction, and all responsibility, is "ours".

The inclusive cooperative community.

When we speak about inclusive housing cooperatives, we do not mean hous-



ing cooperatives entirely made up of people with disabilities, or cooperatives that decide to include a "cluster" of people with disabilities as an after-thought. Ideally, we are talking about a community of friends (disabled and non-disabled alike) who understand the need for community and for mutual support, who will work together to form an inclusive community, and who will remain faithful to the vision and to each other through tough times.

Taking the time for development.

The cooperative community needs to engage in a focused, intensive and sustained process of formation. The community must develop a sense of shared leadership and shared responsibility if it is to meet the inevitable challenges involved in such an enterprise. The organizational and personal tasks which will face the community will be challenging; it will be essential that members of the community enter those experiences with a conviction of shared responsibility. It will be important for the entire community to feel a sense of empowerment and co-commitment.

Every inclusive cooperative is an experiment in

community-building. It will stand (or fall) as an important witness to the possibility of enduring friendship and mutual support between people with disabilities and their friends, families and neighbors. In order for inclusive cooperatives to work, several things must be 'true' at the same time:

First, there needs to be a high ratio of non-handi-

interests and connections, and to help out in practical ways. This requires trust, and trust is something that takes time — it is not 'struck' as part of an occupancy agreement or developed through an orientation meeting.

Second, it is important for the cooperative to 'take care of business' in terms of finances and cooperative



Members of the CHORD/NABORS Cooperatives in Toronto meet for a two-day planning retreat to organize their work as a community (November, 1991)

capped people to people with disabilities, because it will be important for the community to maintain a balance of skills, connections, capacities and income. All members will need people who are willing to share activities,

management. The housing cooperative resource group or mutual housing association will provide education and support in these areas, but the prospects are better if people thoroughly know and trust each other.

Third, building supportive friendships in an inclusive community needs to be a conscious effort. We are simply not accustomed to operating that way. Most people have never heard of the idea of forming an intentional 'circle of friends' with someone who is challenged by disability or who is experiencing isolation. It means actually sitting down together and talking about things, making commitments, following through on those commitments, and staying accountable to each other. And it means celebrating the small victories, the growth of community, and the deepening of friendship.

Fourth, it is crucial to remember that communities are built on capacities and

gifts, and not on disabilities. Everyone has a gift, and it is absolutely essential to talk about, think about and celebrate the gifts of the members, especially those who are labelled handicapped. Everyone of us wants to be recognized for what he or she can contribute; and the opportunity to make a contribution calls us into being the best we can be. Sometimes the gifts are highly visible; sometimes they are invisible, but very important to the success of the community. Community members need to take the time to get to know each other in these ways.

Every intentional community will have its inevitable struggles. People may lose track of the original

vision, go into confusion, try to escape the pain. At these times that the investment which has been made in the initial formation of this community will pay off, as people re-collect their early commitments, and work at once again becoming a whole community.

In Conclusion

We are not proposing cooperative housing as a "solution" for the housing and community needs of people with disabilities. Cooperatives are simply one way to call people together into community. There are many other ways to achieve the combined goals of security, mutual support, and community, even when developing a housing cooperative is not feasible.

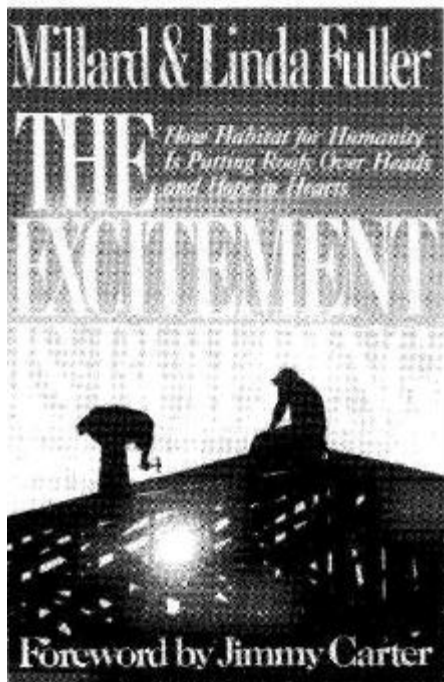
For more information about housing cooperatives, or to explore getting one started, contact a cooperative development resource group or mutual housing association in your community. To locate a resource group in the US, contact the National Association of Housing Cooperatives, 1614 King Street, Alexandria, VA 22314 phone (703) 549-5201, FAX (703) 549-5204.

In Canada, contact the Cooperative Housing Foundation, 275 Bank St., Suite 201, Ottawa, Ont. K2P 2L6, phone (613) 238-4644.



Some of the children involved in the developing CHORD Cooperative in Toronto work on a mural of their dream for community.

HABITAT FOR HUMANITY



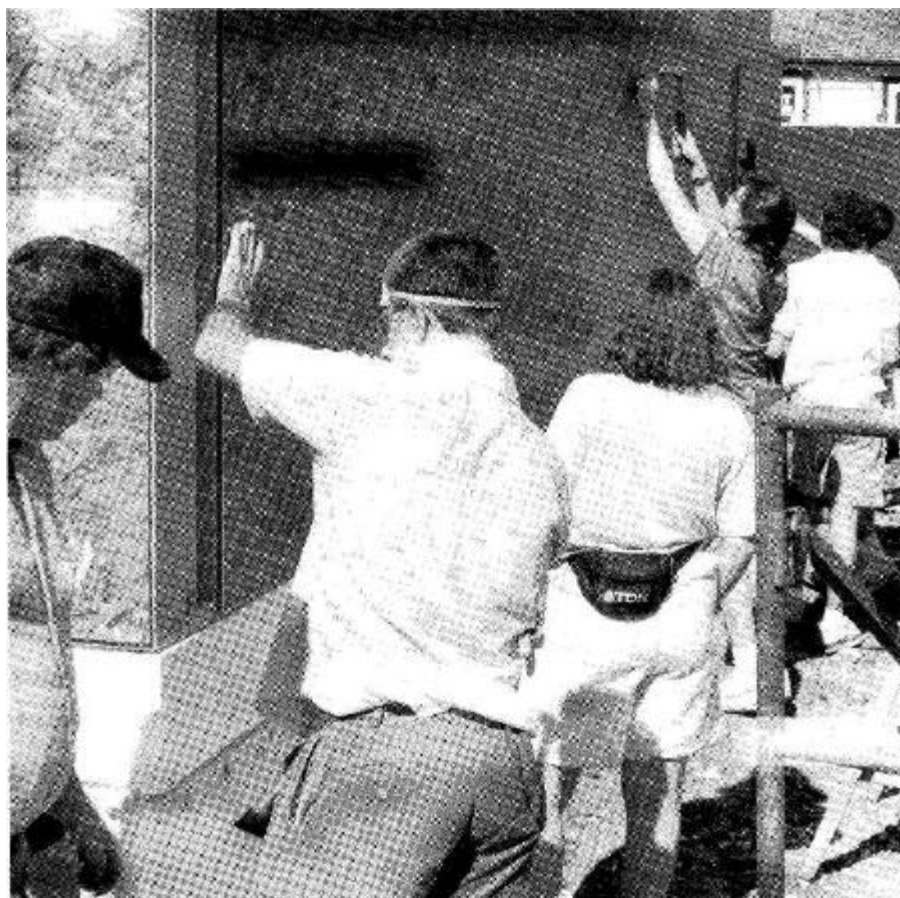
The Excitement is Building:
How Habitat for Humanity is
Putting Roofs Over Heads
and Hope in Hearts, Millard &
Linda Fuller; 1990; 215 pp.;
from Word Publishing

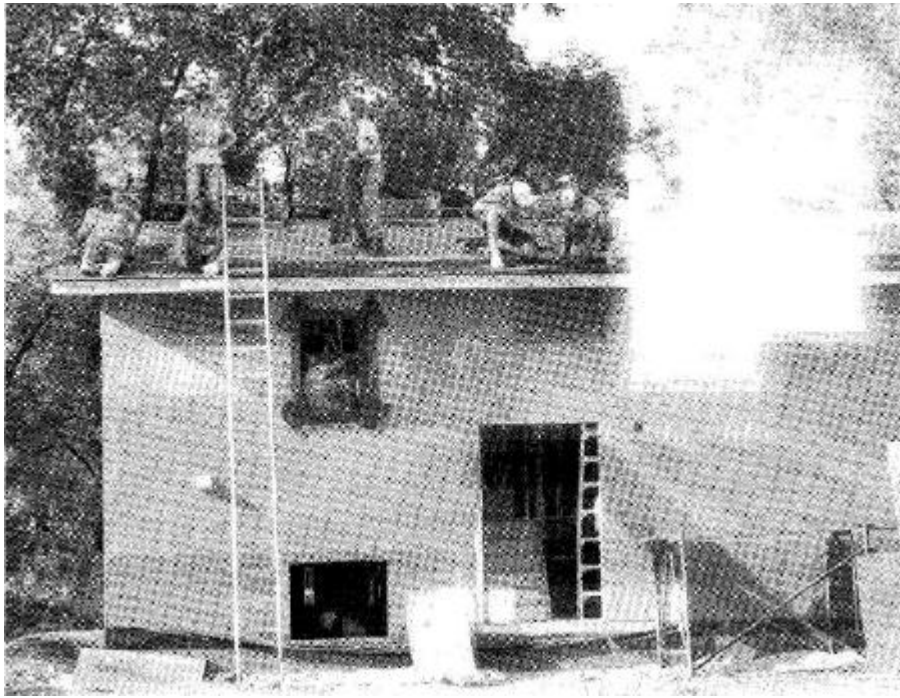
Habitat for Humanity was established in Americus, Georgia, by Millard Fillmore, an American businessman, in 1976. Since then, it has become a world-wide movement, building homes in partnership poor families in 500 cities in 30 nations throughout the world. In Fuller's words:

"The simplest answer I can offer to the question of how to eliminate poverty housing in the world is to make it a matter of conscience. We must do whatever is necessary to cause people to think and act to bring adequate shelter to everyone. And we 'll do this through a spirit of partnership..."

"One of the most exciting features of Habitat for Humanity is that people who don't normally work together at all are coming together to work in this cause: the affluent and the poor; high school students and senior citizens; conservatives and liberals; Roman Catholics and Protestants; and every racial and ethnic group you can think of. We might disagree on how to preach... but we can all pick up a hammer and, sharing the love of God, we can begin to drive nails."

Throughout the world, Habitat affiliates build homes and communities with poor people, financing them





through the sacrificial giving of money and labor by the comparatively rich to help those who are not.

The financing concept is simple and radical: All of the money which builds Habitat houses is donated or loaned to Habitat at no interest. The homes are built in partnership with the people who will own them — "sweat equity" in one's own home and in the homes of one's neighbors is a requirement for partnership. The homes are purchased by the owners on the basis of an interest-free mortgage held by Habitat. Principal payments are cycled back into the building fund, and are used to build additional houses.

The building process is an extraordinary experience. We have witnessed entire houses built and finished — down to the painting, carpets, drapes, and landscaping — in just over four days! Two hundred or more people working together to create a neighborhood in a week — hammering, singing, sharing meals, and building commitment and understanding, as well as houses.

The first Habitat house in Winnipeg was built for a family who had a child with extremely severe disabilities. This family, which had been living in a decrepit storefront, now lives in a fully accessible home, and has literally *hundreds* of friends, a

circle that keeps expanding as they build more houses. When we first met the family and their son, it was clear that this child was going to *need* community. His family's involvement in Habitat is one of the things that will shape his future, and keep him secure.

Habitat may not solve all the housing problems (although Millard Fuller intends that it will). But it stands as a witness to the power of community. If you are struggling with the question of how to provide housing for a family which is struggling with poverty and disability, this is a good connection. Go as a partner.

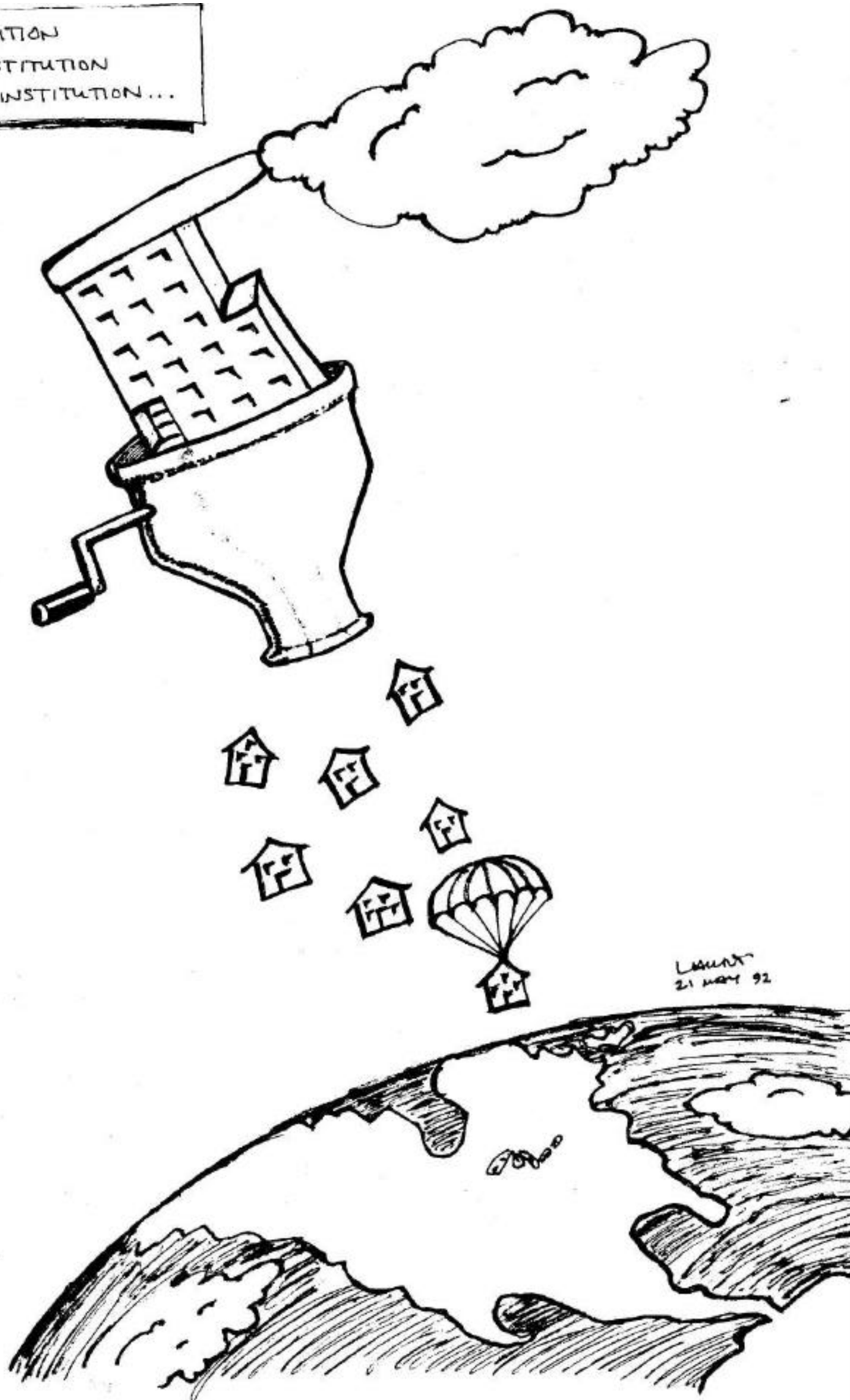
Incidentally, a Habitat "build" provides a wonderful opportunity for people with disabilities to volunteer, to learn (we all do!), to meet dozens of new friends, and to contribute their gifts. Habitat work crews are highly creative about uncovering and using the gifts of everyone who wants to help.

For further information about Habitat for Humanity, or to locate an affiliate group in your area, write or call:

HABITAT FOR HUMANITY HABITAT
& CHURCH STREETS AMERICUS,
GEORGIA 31709-3423 (912) 924-
6935

THE WHOLE COMMUNITY CATALOGUE

AN INSTITUTION
IS AN INSTITUTION
IS AN INSTITUTION...



8.

Vocations

Three years ago, fifty-two families marched on the Legislative building to protest the fact that their disabled sons and daughters had no "day programs," some having left high school up to five years previously. In the long run, the parents got what they came for: the vocational rehabilitation machine cranked out fifty-two more sheltered workshop "slots". But the event did little to change the overall pattern of non-development of vocational opportunities for young people with disabilities. Funding for the fifty-two spaces undoubtedly came out of some other program somewhere else in the system — perhaps highways, perhaps education, most likely some other disability program. The "competitive misery" game was won, at least temporarily, by a group of families who figured out how to put on the pressure. But it didn't change things.

The event had two meanings. First, it meant (exactly as the parents insisted) that government had not done a very good job of counting these young people on the way up through the high school system. Programs had not been planned and developed for the young men and women as they approached the end of their eligibility for secondary school services. The issue probably didn't come up in Legislative estimates. Money was not appropriated. Community groups and non-profit corporations were not engaged to provide new services. As far as we know, another fifty-two (or one hundred and fifty-two, or heaven knows how many) families are getting desperate enough to march on the Legislature next year. It may be some other issue, but the *process* will be the same.

The event meant something else, however — something even more important. It meant that for twenty-one years (on average), fifty two families, extended families, brothers and sisters, grandparents, uncles and aunts, neighbors, friends, colleagues, and church congregations had never considered the possibility that the vocational future of these young people — each of whom they knew intimately -- might lie in their hands.

What it would have looked like if the circle of family and friends around each of those young people had gathered to discuss how they might create solutions to the question of where each of them would work following high school... and had started having that discussion ten years ahead of time. Think about those friends saying, "When John is twenty-one,

he's going to need a job. Let's make a list of all the places where we work and think about opening those places up to John. What is he going to have to know, and who is he going to have to know so that one of us can offer him a job when he gets out of high school? What kind of help will we need to do this?

Each one of the people we mentioned "goes" somewhere during the day. Imagine what might happen if each of those people spent some time thinking out loud about the possibility of John coming to work in their place of employment. Think about the power that each of them has to make the invitation, to introduce the young man or woman to co-workers, other friends, other family members. Think about the range of part-time or summer jobs that John's family and friends could offer over him the course of ten years. What would it be like if they started thinking about John's real vocation ~ about his *gifts* — the unique qualities that he might bring to a work setting?

And finally, think about the power of expanding the definition of work — vocation, in the old sense ~ to include activities that are not part of the world of production/competition / wages. What about the *callings* -- the

vocations — of the artist, the listener, the person of prayer, the comforter?

A friend of ours kept having difficulty with her cleaning jobs in nursing homes because she spent time talking and listening to the people who lived there. She knew the names of all their grandchildren ~ their birthdays, how they were doing. She received the gift that each of the older people had to offer — the stories of their lives — and offered the gift which none of the rest of us had the time or the patience to offer — she was really interested in what they had to say. But she kept getting in trouble, because it interfered with her "job".

Fifty-two families, extended families, friends, neighbors, church members -- times twenty-one years ~ times all of the settings and possibilities that each person represented over the course of those years — it's a staggering potential. And it gets lost, wasted, because John's friends were never encouraged to think about the possibility that his vocational future might come from anywhere other than "the government", or "services for the handicapped."

Even the most responsive public systems — the ones that do plan for the

people coming up through the school system, the ones that get beyond "occupational activity" or "sheltered employment" solutions ~ face major problems in getting the job done.

When the model is one of supported employment in real work settings, it often looks something like strangers accompanying strangers to meet other strangers: job coaches assisting people with disabilities to go knocking on doors looking for jobs -- in a tough labor market — at a time when most businesses are obsessed with "the bottom line". Even in the best systems, the work that friends and families could do ahead of time would make it much more likely that supports from the formal system would actually work.

It would mean that the process of job-seeking and job support would take place among friends — people who know the person, who weren't afraid of the disability, and who start out with a sense of the person's gifts and interests — who just might start from a position of commitment. Then the formal systems supports — and doesn't replace ~ community. Its primary role can be to invite and assist an intact circle of friends and family to create solutions for someone they care for.

Cities and the Wealth of Nations

The winner of the
Los Angeles Times Best Review Award for Non-Fiction

CITIES AND THE WEALTH OF NATIONS

Principles of
Economic Life

JANE JACOBS

Cities and the Wealth of Nations: Principles of Economic Life, Jane Jacobs; 1985; 257 pp.; **\$6.95 US, \$9.50 CDN** from: Vintage Books, a Division of Random House, New York

Ten years ago, when we adopted the model of sup-ported employment as an alternative to sheltered workshops, we found that we were competing for jobs in an economy that was losing jobs at an alarming rate (and still is). It became clear to us that what was needed, at least in our Province, was economic development in general. We didn 't do anything about that idea — after all, what do people in human services know about economic development?

Several years later, John McKnight recommended Cities and the Wealth of Nations, by Canadian economist Jane Jacobs. I've always shied away from economic literature, after a few stabs at Mill, Hume, et. al. In fact, I was certain, after trying to read their works, that I was too dim to understand anything about economics, and just gave up. Jacobs' book was like a breath of fresh air...

People have long observed that poor regions or nations typically import more than they can afford or else are terribly deprived because they fail to produce wide ranges of things for themselves. A poignant description of the shortcoming was contained in a speech made in 1889 by a Southerner to a gathering of industrialists and bankers in Boston—Henry Grady, an essayist and the editor of the leading newspaper in Atlanta, Georgia, told of a funeral he said he had attended a few years previously in Pickens County, some eighty miles north of Atlanta.

The grave was dug through solid marble, but the marble headstone came from Vermont. It was in a pine wilderness but the pine coffin came from Cincinnati. An iron mountain over-shadowed it but the coffin nails and the screws and the shovel came

from Pittsburgh. With hard wood and metal abounding, the corpse was hauled on a wagon from South Bend, Indiana. A hickory grove grew nearby, but the pick and shovel handles came from New York. The cotton shirt on the dead man came from Cincinnati, the coat and breeches from Chicago, the shoes from Boston; the folded hands were encased in white gloves from New York, and round the poor neck, which had work all its living days the bondage of lost opportunity, was twisted a cheap cravat from Philadelphia. That country, so rich in undeveloped resources, furnished nothing for the funeral except the corpse and the hole in the ground and would probably have imported both of those if it could have done so. And as this poor fellow was lowered to his rest, on coffin bands from Lowell, he carried nothing into the next world as a reminder of his home in this, save the halted blood in his veins, the chilled marrow in his bones, and the echo of the dull clods that fell on his coffin lid.

Jacobs goes on to explain in clear, unmistakable, practical terms, how a local economy is developed. Her writing raises the possibility of building enterprises with the potential to include people with disabilities. Pure inspiration.

Creating Diversity

Creating Diversity: Organizing and sustaining workplaces that support employees with disabilities, Bruce Anderson & Margaret Andrews; 51 pp.; **\$7.00** from: Centre for Community 700 Katlian St. - Suite B Sitka, Alaska 99835 (907) 747-6960

Over the last couple of years, there has been a rapidly growing interest in the idea that employee "diversity" is a good thing for work places of all kinds. Many employers are saying that the benefits of diversity can be measured in actual production rates and employee satisfaction. Government and non-profit agencies who specialize in employee issues have been attempting to capitalize on the diversity bandwagon by convincing employers to hire people with disabilities.

For several very sound reasons, some managers have been hesitant to respond to government requests to employ more people with disabilities. They know that getting involved with government or social agencies often results in:

- increased paperwork, regulations, and time away from the tasks at hand.
- getting into time consuming relationships with social service workers who may have

little knowledge about how the business operates, and scant respect for the value of time and efficiency.

-the possibility of a social worker actually being in the workplace assisting the new employee who has a disability. This usually disrupts the workplace flow, and sends the added negative message that people with disabilities need special help from experts, and that other employees aren't capable of solving workplace problems. This works directly against the growing cry of managers who are trying to give more power and control the lower level employees.

This booklet is written in response to those management concerns. It claims that businesses do want to help, on their own terms, without excessive intervention from government or social service agencies. What these businesses need is a different kind of assistance than is currently being provided by social service agencies. Given the opportunity and some basic problem solving assistance, employees are able to figure out how to include co-workers with disabilities in workplace tasks.

If you have a commitment to hiring different kinds of people to work in your business, and would like to do it without the usual procession of paperwork and people, this booklet is for you. It provides a step by step process for setting up a workplace to

accommodate employees with disabilities using existing employee expertise to increase efficiency, build employee problem solving skills, increase production, and create stronger relationships and mutual trust amongst all employees.

This is the first publication we know of that tries to put together community-building relationships, current business "quality management" principles, person-centered planning strategies, and respectful values applied specifically to employment situations for people with disabilities.

If s a good book to share with to business owners and personnel managers who want to hire employees with disabilities without depending so much on social service agencies. We think it's the only publication currently available that specifically deals with the issue of hiring employees with disabilities without going through the usual programs and agencies.

Managers who have a healthy skepticism for government employment programs have taken a special delight in the tone of this publication, which claims that some of the work done by employment agencies is actually destructive to the way that businesses operate. The booklet takes a few well-deserved pokes at social service agencies and their employees, and asks hard questions about who is really responsible for employing people with disabilities.

You can Learn a Lot from a Tofu Kingpin

BY BRUCE ANDERSON

(At the time of this writing Bruce Anderson co-managed the Community Resource Network in Sitka, Alaska and Vashon, Washington. The organization offers a toll-free telephone assistance line to people in Alaska who have chosen to offer support to neighbors and friends who have disabilities.)

Our friend, Sue, called yesterday afternoon from Juneau just to say hello and let us know how things were going with the family she is helping to support. She described many great things happening, and also wanted to talk about her frustration and disappointments in getting people outside of service systems involved. As we talked about some ideas and chatted back and forth, I could tell she was very frustrated. We talked for a while longer, and said good-bye.

After that phone call, I slumped in my chair gazing blankly out the window, reflecting on my talk with Sue. I was feeling discouraged, and realized that my day had been filled with calls on the 800 assistance line

from people who were up against what seemed to them like hopeless situations. Their frustration and disappointment had filled me with sadness and anger. Often times, I am painfully aware that the emotional support and problem solving assistance that I have to offer does not come close to what is needed ... and I recognize my own limitations.

As I was stewing in my sadness and frustration, a man walked quickly into the office unannounced. He was tall, and carried himself with pride. His name, he told me, was Luke Lukoskie, and he was the founder and President of Island Springs Tofu Corporation. I had seen his product in many grocery stores, and knew from newspaper articles that his company was a major employer, and that Mr. Lukoskie was an inventive and aggressive businessman.

Luke said he had been walking by our office for several months, and was curious about what our company did. I told him we worked on many different kinds of activities that supported people with disabilities in living and working in communities. (I'm always at a loss to briefly explain what we do) He asked me a few questions. Then, I'm sure in an effort to find some com-

mon conversation between us, he mentioned that he currently had an employee who had a developmental disability. I brightened at his remark, and quickly asked him how it was going with that employee. He informed me that everything was great with all his employees, and that, just in case we were considering it, he was sure he wouldn't be needing any help from our organization. We talked some more, and he asked if we could help him get connected with any people in our town who really needed a job and were having a tough time finding one. Gina mentioned our friend Glenn, who recently moved out of a State institution to a town close to us. We described all the things we thought that Glenn could contribute to a company like Island Springs, and also mentioned that sometimes Glenn gets pretty mad at people around him, and that has made it hard for him to hold jobs in the past. Much of his anger, of course, is the result of being locked up in an institution for 36 of the 54 years he has been alive. Luke's reply to us was, "We're all a bunch of real misfits at my company, and it sounds like Glen would fit in just fine. Tell him to come on over, next time you talk to him."

(continued overleaf)

I had to leave the office to go to a meeting, and I walked out to the parking lot with Luke Lukoskie. As we got to the cars, he asked me which one was mine. It seemed like an odd question, so as I pointed to my car I asked why he wanted to know. He looked at me like I should already know the answer and replied, "I'd like to be able to easily recognize you when we drive by each other, so I can wave."

It's now the next morning, and I can't get either Luke or Susan out of my mind. The contrast is stark and filled with opportunity. In one place sits Susan, frustrated that she is having a hard time finding anyone outside of paid service system people who she can depend on. In another place stands Luke, a man who is eager and capable of offering help, but doesn't know where to look.

As I think about them, I am sure of two things. First, that there are many Susans and Lukes in all of our communities. To deny that either of them exists in abundant quantity is to be blind to what communities are made of. Secondly, for any community to survive as a healthy place absolutely depends on those two people meeting and offering themselves to each other.

There are several things that Luke and Susan have helped me to remember this morning. First, they have reminded me that the gifts people have to offer each other are discovered face to face, and cannot and will not be realized in the old ways that we have tried. It must become the main purpose of government systems and all individuals living in a place to help community members connect with each other. Secondly, I am grateful that I have released myself from the agonizing confusion that I see so often in people who are not yet convinced that the Lukes of the world exist. I no longer need to spend time and energy deciding if he exists... I am certain that he does. My job, now, is only to find him. And in my darkest moments, I must never forget that I know he is out there, and that I am free to use the power behind that belief to give me strength to keep going. Third, and most importantly, I am reminded that so much of what happens to all of us is either chance, magic, or part of some higher purpose that I am not able to understand or predict. What was it that made Luke Lukoskie walk through that door just when I needed him? What I do know is that his presence in my life yesterday has given me the gift of a story, and the courage to spend one more

day helping people to see what may be possible, if they will open their hearts to the possibility that Luke Lukoskie will walk through their door.

?

[THERE IS]...A WISDOM TO BE FOUND IN THE PEOPLE. AND ONCE IN A GREAT WHILE AN *ISUMATAQ* BECOMES APPARENT, A PERSON WHO CAN CREATE THE ATMOSPHERE IN WHICH WISDOM SHOWS ITSELF.

THIS IS A TIMELESS WISDOM THAT SURVIVES FAILED HUMAN ECONOMIES. IT SURVIVES WARS. IT SURVIVES DEFINITION. IT IS A NAMELESS WISDOM ESTEEMED BY ALL PEOPLE. IT IS UNDERSTANDING HOW TO LIVE A DECENT LIFE, HOW TO BEHAVE PROPERLY TOWARD OTHER PEOPLE AND TOWARD THE LAND.

IT IS, FURTHER, A WISDOM NOT OWNED BY ANYONE, NOR ABOUT WHICH ONE CULTURE IS MORE INSIGHTFUL OR ARTICULATE. I COULD EASILY IMAGINE SOME THOMAS MERTON-LIKE PERSON, THE ESTIMABLE RATHER THAN THE FAMOUS PEOPLE OF OUR AGE, SITTING WITH ONE OR TWO ESKIMO MEN AND WOMEN IN A COASTAL VILLAGE, CORROBORATING THE EXISTENCE OF THIS HUMAN WISDOM IN YET ANOTHER REGION OF THE WORLD, AND LOOKING AROUND TO THE MOUNTAINS, THE ICE, THE BIRDS TO SEE WHAT MAKES IT POSSIBLE TO PUT IT INTO WORDS.

- BARRY LOPEZ
ARCTIC DREAMS

9.

Networks

Resources

Church of the Savior and The Servant Leadership School

1640 Columbia Road, N.W.
Washington D.C. 20009
(202)328-7312

The church of the Savior in Washington, D.C. in the Adams Morgan Section of the City is, in our opinion, one of the most eloquent examples that we have found of welcoming all people - the inclusion of people with diversity into the life of a community association. A restaurant community, The Potter's House, a bookstore, a medical centre, a residential centre, a L'Arche community and most recently the Servant Leadership School and a Retreat Center all have emerged from the discernment of gifts and people from within their church. From our perspective, the discernment and encouragement of individual gifts is a way to be understood, learned, and duplicated by those of us who

are interested in bringing people with disabilities and their gifts closer to community life. There are many books and a location to visit -we particularly recommend books by founders Gordon Cosby and his wife Elizabeth O'Connor.

Communitas, Inc.

Box 374
Manchester, CT 06040
(203) 645-8034

Communitas is an international non-profit network designed to create connections between people who are working on the full inclusion of all people into community life.

Co-Op Initiatives

Exec. Director: Sarah Page
60 Lorraine Street Hartford,
CT06105 (203) 523-0890

Co-op Initiatives was founded in 1988 and incorporated as a private non-profit housing development organization in 1989. The primary goal of Co-op Initiatives is to create limited equity housing cooperatives which are designed to create a support network around people with developmental disabilities. Co-op Initiatives will create affordable housing which is socially integrated, benefiting many low and moderate income families, as well as people with developmental disabili-

ties. The co-ops are structured as mixed income developments in order to create socioeconomic balance and have a healthy economic composition.

Cooperative Fund of New England

108 Kenyon Street
Hartford, CT 06105

Rebecca Dunn
Executive Director
(203) 523-4305

The Cooperative Fund is an alternative financial organization supporting cooperative development in New England. Organized in 1975 through the joint efforts of co-op activists and social investors, the Fund is dedicated to providing a vital link-up between needy but promising co-ops and persons with available financial and technical resources. The Fund is funded by social investors interested in the constructive social use of their money.

In 1990, the fund began a Community Living project which enables people with developmental disabilities to use a loan/loss reserve to move into housing co-ops or other desegregated independent living options. In addition, the Fund intends to initiate a form of peer lending among people with disabilities in the community.

- ED PRENETA

Small Towns Institute

P.O. Box 517, Ellensburg,
Washington 98926 (509)925-
1830.

As its name indicates, this organization is devoted to gathering and making available information and ideas about life in small communities in North America. The institute publishes a bi-monthly magazine entitled *Small Town* that, according to its editor, "...brings together the interests of a broad spectrum of people and organizations concerned with community well-being."

Naturally, a part of this "broad spectrum" is the point-of-view of professional planners in universities and local government agencies, and the magazine has lots of content that comes from that sector. It's not all that sort of thing, though. A recent issue included articles about citizen organizing for social change, about tree-planting by citizens, and about developing community "greenways". In the same issue the editor reminds us that: "Small towns are not Utopias. They are messy, complicated, lively and intricate places. Therefore, we who choose to live in small communities need to understand that the problems with local people that sometimes plague us actually stem from the complications of living so close together."

Periodicals

Citizen Advocacy Forum

Editor: A.J. Hildebrand
\$20.00 US **\$22.00** Canada
\$25.00 Overseas
Subscriptions in US funds to:
Citizen Advocacy Forum P.O.
Box 86 Beaver, PA 15009
(412) 775-4121

The Forum is a collective effort supported by an active editorial board of people who have had extensive experience in Citizen Advocacy. Probably the best single connection to developments in the C/A movement.

The Common Thread

Editor: Sharon Gretz
17A Eisele Road
Cheswick, PA 15024

The Common Thread is a publication of the Community Building Project at UCP Pittsburgh, funded by the Pennsylvania Developmental Disabilities Council. It highlights a number of innovation projects scattered throughout Pennsylvania, as well as operating as an exchange of information, stories and resources about community/relationship building.

Communitas Communicator

Editor: Catherine D. Ludlum
\$15.00 from:
Communitas, Inc.
Box 374
Manchester, CT 06040
(203) 645-8034

Communitas is an international non-profit network designed to create connections between people who are working on the inclusion of all people into community life. The newsletter compiles stories, ideas, and resources from a growing network of community-builders.

Co-Op Initiatives News

Editors: Catherine D. Ludlum,
Sarah Page 60 Lorraine
Street Hartford, CT06105
(203) 523-0890

A solid all-around guide to resources and connections for people interested in developing *inclusive* housing cooperatives. A rich source of ideas and practical information about financing, funding personal support systems, accessing relevant housing programs, member education and community-building.

Co-Op Update

Madison Mutual Housing
Association and Cooperative
Tenney Building, Suite 615
110 E. Main Street Madison,
WI 53703 (608) 255-6642

MHA is a seasoned non-profit
developer of cooperative
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Louisville, KY 40201

Inclusion News

Marsha Forest & Jack
Pearpoint, Editors
Centre for Integrated
Education and Community
24 Thome Crescent Toronto,
Ontario M6H 2S5

This catalogue contains a
number articles and reviews
by the team of Marsha For-

est, Jack Pearpoint and Judith
Snow. Inclusion News is a
good way of keeping up-to-
date on what they (and
others) are doing, discover-
ing, and thinking about in the
realm of inclusive education.
It is an "occasional publica-
tion"; presently there are no
subscriptions. We suggest
that you include a donation
with your request to get on
Inclusion News' mailing list,
since it is funded entirely
independently.

Parabola: The Magazine of Myth and Tradition

Hospitality, in the deepest
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and community inclusion. The
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and modern forms. When
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and handling to: Parabola 656
Broadway New York, NY
10012

Qaillun Ikaiyucarcia

Alaska Family Resource
Project
Bruce Anderson, Editor
Community Resource Network
P.O. Box 6049
Sitka, Alaska 99835, or
P.O. Box 328
Vashon, Washington 98070

This project was designed to
give power back to people

and communities who, in the
past, have relied for the most
part on paid service systems
and professional help. Write
for their Winter 91/92 news-
letter and find out how.

The Safeguards Letter

Editor: Jack Pealer Ohio
Safeguards P.O. Box
1943 Chillicothe, Ohio
45601

Jack Pealer keeps coming up
with powerful insights, ideas
and connections about com-
munity empowerment, and
regeneration.

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Syracuse, NY 13244-2280

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renewal (to afflict the com-
fortable), I reserve as my
highest compliment for a
presentation the description
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TIPS to be a disturbing expe-
rience. Disturbing, one might
say, to the sediment accumu-
lated along the bottom of my
stream of consciousness.
Disturbing by challenging

settled opinions, by forcing the reader to ask whether a given opinion about one's work, or world, or self is truly consistent with one's values. Disturbing by reminding me of the nature of the world we live in and the times we live in, bringing the disturbing news off the AP wire as well as the disturbing articles out of the professional journals and linking those signs to the broader and deeper trends which affect us all.

Catalogues

Expectations Unlimited

P.O. Box 655
Niwot, Colorado 80544
(303) 652-2727

This exciting collection of recordings and writings reflects many new experiences and beliefs regarding the importance of including *all* children in school. Well-selected materials from leaders in the field, speaking to a variety of subjects.

Human Policy Press

Center on Human Policy
Syracuse University School
of Education 200 Huntington
Hall, Syracuse, NY 13244-
2340

Human Policy Press is an independent press, established by the Center on Human Policy in 1971, to

promote positive attitudes towards people of all ability levels. In the 1990's, the press continues as a strong voice for all the full integration of people with disabilities in the community. The press makes available media packages, buttons, posters, books, slide shows, and videotapes that aim to fulfill the goal of improving society's literacy about people with disabilities.

The Center on Human Policy has developed a variety of reports and resources in the integration of people with severe disabilities into community life. These reports and resources are useful for people with disabilities, advocates, parents, service providers, policy makers, and people interested in thinking about communities that include everyone. The Press produces information packages, reports based on site visits to community programs around the country, resource materials on community integration, evaluations and studies, papers and articles, and advocacy reports. These reports and resources were developed through the Center's Research and Training Center on Community Integration and its sub-contracts with, the University of Minnesota's Research and Training Center on Community Living and Responsive Systems Associates in

Lithonia, Georgia. For a complete listing, please write to the Center on Human Policy.

Inclusion Press

24 Thome Crescent
Toronto, Ont. M6H 2S5
(416) 658-5363

Inclusion Press is a small independent press producing readable, jargon-free, user-friendly books and other resources on the topic of full inclusion in school, work, and community. Their books are excellent resource materials for courses and conferences. Write or call for information re bulk rates for schools and voluntary/advocacy organizations. Inclusion Press can recommend packages of materials for conferences, workshops, and staff development seminars.

The Roeher Institute

Canadian Association for
Community Living
Kinsmen Building
York University
4700 Keele Street
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(416)661-9611

The Roeher Institute maintains holdings in a wide range of areas, with a major focus on public policy, studies of innovative social programs and the development of policy alternatives. Information services include a computer accessible data base.

Training

The Training Institute for Human Service Planning, Leadership & Change Agency

Wolf Wolfensberger, Director

Course announcements and schedules are available from:

Training Coordinator
Training Institute
805 South Crouse Avenue
Syracuse University
Syracuse, NY 13244-2280
(315)443-4264

Wolf Wolfensberger provided the conceptual framework, the training, and the discipline that got most of us started. Training Institute events are challenging, demanding, and incredibly enlightening. Not an easy path, but an essential set of tools and ideas, from the personal, system, and global perspective. Well worth the investment of time, energy, and travel. Here is one example:

The Training Institute offers a 2-3 day workshop on the importance of recruiting voluntary personal and communal relationship commitments to devalued and otherwise vulnerable people, by valued and competent per-

sons. In this event, the problems of organized human services and of the society as a whole are reviewed, including formaliza-tion, complexity, and the hidden functions and purposes of human service agencies to make and keep people dependent.

The event proposes that in order to liberate people from dependence on such a destructive system, it is necessary to recruit freely-given relationship commitments to them from valued and competent people, that are not tied to a job or profession.

The event explains some of the forms that such commitments can take, and how they can offer some security and protection to vulnerable people in a social order that is collapsing -- as is ours, and as the workshop explains.

The event serves primarily to raise consciousness as to the utter hopelessness of organized service structure in the current societal context, and to teach participants that the recruitment of voluntary commitments by valued people to devalued ones is not just desirable, but imperative.

Interested parties can contact the Training Institute for a more detailed description of the event, and to negotiate

details of dates and finances if they would like to bring such an event to their locale.

Highlander Research & Education Center

1959 Highlander Way, New Market, Tennessee 37820
(615)933-3443.

Highlander (formerly the Highlander Folk School) has been active since 1932 at trying to work for economic and social justice in the (mostly rural) southern states of the U.S.

Founded by Myles Horton, Highlander's work is based on the notion that people who live in unjust conditions can work powerfully for change if their own experiences and insights can be unleashed through adult education. This is education not of the course-work kind, but of the kind that gathers ordinary people together in a safe place to share their experiences, practice analyzing those experiences, and make decisions about what they might do to change conditions in their communities (and, therefore, in the nation and world) for the future.

The work of Highlander and its exciting history are described in: The Long Haul: An Autobiography by Myles Horton (with Judith Kohl and Herbert Kohl); 1990; Doubleday, New York

The Summer Institute in Integrated Education and Community: An International Event
Marsha Forest and Evelyn Lusthaus, Directors

Each summer, after the fourth of July and Canada Day, over 225 dedicated people arrive on the campus of Montreal's McGill University for the Annual International Summer Institute in Integrated Education and Community. This two week intensive learning experience has become an exciting "community of scholars" delving into the issues and practices of inclusive education and community building.

The Summer Institute is an innovative immersion program focusing on strategies for the integration of people with challenging needs into schools and community. Courses for 1992 will include: Action for Inclusion - The Learning Community; The Challenge of Changing a School System; Strategies for Day to Day in the Classroom; Working for People with Difficult Behavior; Building Communities of Diversity.

The Institute has always been more than simply courses. It is an attempt to build a cooperative and inclusive learning environment. The Institute strives to meet a variety of adult learn-

ing needs and styles by having a mix of workshops which include more traditional styles, and other more experimental and alternative approaches.

The mix of students is an ingredient that makes the Summer Institute unique. Parents of children with challenging needs are encouraged to attend. Limited scholarships have been found for both parents and self advocates. Members of groups such as People First are a vital part of the community.

Past and present faculty have included John O'Brien, John McKnight, Susan and Bill Stainback, Gordon Porter, Marsha Forest, Jack Pearpoint, Judith Snow, Herb Lovett, Jan Nesbitt, Jay Klein, George Flynn, Alison Ford, Doug Biklen, Sari Biklen, Harry Silverman, Evelyn Lusthaus, Michael Giangreco, Michael Callahan.

For further information about the Institute, write: Evelyn Lusthaus McGill Summer Institute Faculty of Education 3700 McTavish Street, Montreal, Quebec Canada H3A1Y2 Phone (514) 398-4242 Fax (514)398-6968.

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Thanks!

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To Get in Touch with Us:

David Wetherow

The Community Institute
P.O.B. 23036 1315
Pembina Highway
Winnipeg, Manitoba
CANADA R3T 2B6
(204) 284-7768 - evenings

The Association for
Community Living - Winnipeg
1706-90 Garry Street
Winnipeg, Manitoba R3C 4J4
(204) 947-1249-days

George Ducharme and Pat Beeman

Communitas, Inc.
P.O.B. 374
Manchester, Connecticut USA
06040 (203) 645-8034

Other Contributors:

c/o Communitas, Inc.
P.O.B. 374
Manchester, Connecticut USA
06040 (203) 645-8034

For Now, a Few Last Words:

Everything should be made as simple as possible... but not simpler.

Albert Einstein

I am trying to make a building which is like a smile on a person's face... and which has that kind of Tightness about it... [You know] the sort of incredible way you reverberate when someone smiles at you, and the way you feel... When someone smiles it is as though the fabric of the universe seems to melt. *In other words, something happens in that the order of things actually relaxes in a peculiar way. And it can happen in a million different ways.*

- Christopher Alexander, quoted in Christopher Alexander: The Search for a New Paradigm in Architecture, by Stephen Grabow, Oriel Press, 1983

Because the condition of marriage is worldly and its meaning communal, no one party to it can be solely in charge. What you alone think it ought to be, it is not going to be. Where you alone think you want it to go, it is not going to go. It is not going where the two of you - and marriage, time, life, history, and the world - will take it. You do not know the road; you have committed your life to a way.

- Wendell Berry
Standing by Words

And still I am learning.

- Michaelangelo

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